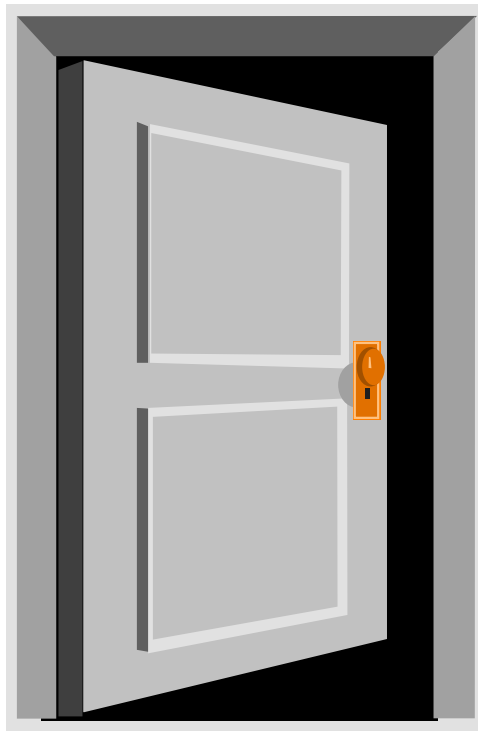


Personal Life Quality Protocol

Generic Complete Version 4.8



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Personal Life Quality Protocol

Generic Complete Version

Table of Contents

General Information`	3
General Instructions	4
Individual Descriptive Information	5
Living Situation and History	7
Current Abilities	9
Orientation Toward Productive Activities Scale	14
Adjustment And Challenges Scale:	16
Individual Budget Information	17
Individual Planning and Supports (Past 12 Months Only)	19
Individual Plan Summary (Top 5 Goals)	22
“Traditional” Services/Supports	23
Weekday Routine and Activities	24
Daytime Activity Program, Work, and School	24
Connections with Family and Friends	26
Close Friends Scale	27
Decision Control Inventory 1: For All People	28
Decision Control Inventory 2: For People Living With Family or Friends	29
Integrative Activities During the Past Month	30
Health Information	31
Questions To Be Asked of the Respondent Who Knows the Person Best	34
Qualities of Work Life, Before Self-Determination, and Now	35
Qualities of Work Life, Before Self-Determination, and Now	36
Quality of Life Changes	37
Personal Interview	37
Individualized Practices Scale	44
Home Physical Quality Scale	46
Elements Of Normalization	48
Visitor's Subjective Impressions	49
Scale On Advocacy And Rights (SOAR)	50

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General Information

Focus Person:

1. _____ 2. _____ 3. _____
First Name M.I. Last Name

4. _____ - _____ - _____ 5. _____
Social Security Number Individual Identification Number

6. _____
Person's Complete Mailing Address, Including Apartment #, Line 1

7. _____
Person's Complete Mailing Address, Including Apartment #, Line 2

8. _____ 9. _____ 10. _____
City or Town State Zip Code

11. _____ 12. _____
Telephone Number of the Home Residential Facility Number

Support Providers:

13. _____ 14. _____
Oversight Agency Name Agency Phone #

15. _____ 16. _____
Agency That Provides Residential Supports (If Any) Agency Phone #

Respondents:

17. _____ 18. _____
Primary Respondent's Name Title or Relationship to Person

19. _____ 20. _____
Name of Person Completing This Protocol Title or Relationship to Person

21. _____ / _____ / _____
Today's Date

General Instructions

This package is composed of many measures, scales, instruments, and interview items. Practically all of the information collected in this package is related to quality of life. In order to complete the package, you must have access to:

1. The person (to attempt a direct interview of any length, usually 5 to 15 minutes)
2. Whoever knows the individual best on a day to day basis (about 30 to 60 minutes)
3. The person's records, including medical records (about 5 to 10 minutes)
4. Sometimes, a health care professional familiar with the person (about 5 to 10 minutes)

Multiple informants, or respondents, are perfectly OK if they are willing to give their time. With access to these four sources of information, and after some practice sessions, you will probably be able to complete this package within the range of 45 to 95 minutes. The first time out, however, will probably take well over 2, and possibly even 3, hours. After that, the process should speed up. One key item to remember is that many of the questions explicitly contain the word "ABOUT." In these cases, estimates are fine. You need not spend a long time looking for documentation on such questions.

Sample Introductory Statement For Visitors (May Be Paraphrased As Needed)

I am _____, and I am working on a project for the [Agency]. We are working to track the well-being of people when they get involved with self-determination, individual budgets, and person-centered planning. Today, I am visiting _____, and collecting information about his/her situation and qualities of life.

I will need about 5 to 10 minutes privately with the person, and about an hour to an hour and a half with whoever knows the person best on a day to day basis. I will also need access to records, and possibly will need to talk very briefly with someone who knows finances, and/or a knowledgeable health care professional.

By conducting these visits and collecting information about the person's life, we will be able to scientifically document changes in the person's qualities of life during the years to come. Areas of quality include many factors, such as the person's satisfaction, family satisfaction, types and amounts of services and supports, health, health care, progress toward increased independence, self-determination, productivity, integration, and quality of home and work settings.

Any questions about this project can be directed to *[Insert local coordinator name and phone]*.

Individual Descriptive Information

1. DATE OF BIRTH

____ - ____ - ____
Month Day Year

2. AGE

3. GENDER

1 Male

_____ 2 Female

4. PRIMARY ETHNICITY

1 Indian/Alaskan

2 Asian/Pacific

3 White, Caucasian

_____ 4 Black, African-American

5 Hispanic, Latino

6 Other

7 Unknown

5. For Children 0-5 Years, Developmental Delay:

0 No developmental delay

1 One delay

_____ 2 More than one delay

9 Not applicable

6. For ages 6 and up: LEVEL OF MENTAL RETARDATION LABEL (IF ANY)

0 None, not labeled with mental retardation

1 Mild

_____ 2 Moderate

3 Severe

4 Profound

9 Unknown

7. OTHER DISABILITIES

0 = No disability

1 = Some disability

2 = Major disability

- _____ 7A. Ambulation (Walking)
- _____ 7B. Autism
- _____ 7C. Behavior: Aggressive or Destructive
- _____ 7D. Behavior: Self Abusive
- _____ 7E. Brain Injury
- _____ 7F. Cerebral Palsy
- _____ 7G. Communication
- _____ 7H. Dementia (Including Alzheimer's Disease)
- _____ 7I. Health Problems _____
- _____ 7J. Hearing _____
- _____ 7K. Mental Illness _____
- _____ 7L. Physical Disability Other Than Ambulation: _____
- _____ 7M. Seizures
- _____ 7N. Substance Abuse: _____
- _____ 7O. Vision
- _____ 7P. Other (s) _____

8. LEGAL STATUS

- _____ 1 Parent or other relative is full guardian
- _____ 2 Parent or other relative is limited guardian
- _____ 3 Unrelated person is full guardian
- _____ 4 Unrelated person is limited guardian
- _____ 5 Person has no guardian or is own guardian, not adjudicated incompetent

9. SELF-DETERMINATION: Is this person participating in a Self-Determination Project?

- _____ 0 No (Skip next question)
- _____ 1 Yes

10. FOR HOW LONG? For about how many months so far? You may write "0" for those who are not yet involved. (We recognize that a "beginning date" may be very hard to define, so please write in your best estimate after discussion.)

_____ months

11. WHAT CRITERION WAS USED TO ANSWER QUESTION # 10? Please choose one.

- _____ 1. Person Centered Planning Began
- _____ 2. Person Centered Plan was Agreed To/Signed
- _____ 3. Began Designing Individual Budget
- _____ 4. Gained Control of an Individual Budget
- _____ 5. Other Criterion (Please Describe _____)

Living Situation and History

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1. TYPE OF HOME (Current):

- 1 Own Home
- 2 Parents' or Other Relatives' Home
- 3 Supported Living in Community (not a group home)
- 4 Supervised Community Residence (Group Home)
- _____ 5 Foster Home, non-relatives
- _____ 6 Foster Home, relatives
- _____ 7 Nursing Home
- _____ 8 Developmental Center
- _____ 9 Other _____

2. WHO CHOSE THIS HOME?

- 1 Professionals chose this home
- 2 Professionals chose this home with input from person and/or family (guardian)
- 3 Family (guardian) chose this home
- _____ 4 Person and family (guardian) chose this home
- _____ 5 Person chose this home
- _____ 6 Other _____

3. HOME OWNERSHIP: Does the person have any ownership interest in this home?

- 1 No, not at all (agency or government or others own this home)
- 2 Yes, minor part of ownership
- _____ 3 Yes, major part of ownership
- _____ 4 Yes, wholly owned by person
- _____ 9 Not Applicable (this home is rented or is used via some other arrangement)

4. IF HOME IS RENTED, IS THE PERSON'S NAME ON THE LEASE OR RENTAL AGREEMENT?

- 0 No
- 1 Yes, and so is the agency or government
- 2 Yes, and so is agency or government and relative/guardian/friend
- _____ 3 Yes, and so is relative/guardian/friend
- _____ 4 Yes, and so are one or more cohabitants
- _____ 5 Yes, only this person's name is on the lease
- _____ 9 N/A

5. HOW MANY PEOPLE LIVE IN THIS HOME? (Cottage or living unit or building or wing or other meaningful subunit if this is a State Hospital or other congregate facility. If this is a community home, then please define home as a distinct **mailing address**.)

5A. _____ People with disabilities (including this person)

5B. _____ People without disabilities (unpaid cohabitants, including friends, parents, and other family members.)

5C. _____ Paid staff who live here (paid cohabitants)

6. HOW MANY STAFF WORK IN OR AT THIS HOME? (Counting all shifts, and only count staff who are physically present at the home regularly, not staff who make phone contacts or staff who monitor alarm devices.)

6A. _____ Full Time Staff (Enter 0 if none or 99 for NOT APPLICABLE, such as Independent Living)

6B. _____ Part Time Staff (Enter 0 if none or 99 for NOT APPLICABLE, such as Independent Living)

7. WITH HOW MANY OTHER PEOPLE DOES THIS PERSON SHARE A BEDROOM?

_____ People

8. PREVIOUS TYPE OF HOME (Use same codes as #1 above)

_____ (88 if none, 99 if unknown)

9. DATE LEFT THAT HOME (AND CAME HERE)

_____/_____
Month Year (88/88 if N/A, 99/99 if unknown)

10. THE TYPE OF HOME BEFORE THAT? (Same codes as #1.)

_____ (88 if none, 99 if unknown)

11. DATE LEFT THAT HOME?

_____/_____
Month Year (88/88 if N/A, 99/99 if unknown)

12. HOW MANY TIMES IN THE PAST YEAR HAS THIS PERSON MOVED (CHANGED ADDRESSES)?

_____ times

13. DID THIS PERSON EVER LIVE IN ANY PUBLIC OR PRIVATE SETTING OF MORE THAN 15 BEDS? (These large settings are often called institutions or congregate care facilities.)

0 No
_____ 1 Yes

14. IF YES, WHEN DID HE/SHE LAST LEAVE THAT LARGE OR INSTITUTIONAL SETTING?

_____/_____
Month Year (88/88 if N/A, 99/99 if unknown)

15. ABOUT HOW MANY YEARS OF THIS PERSON'S LIFE HAVE BEEN SPENT IN LARGE CONGREGATE SETTINGS (STATE DEVELOPMENTAL CENTERS, ORPHANAGES, HOSPITALS, DETENTION CENTERS, PRISONS, ETC. OF MORE THAN 15 BEDS)

_____ Years (Enter 0 if none, 99 if Don't Know)

Current Abilities

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GENERAL INSTRUCTIONS

1. This information is to be obtained BY INTERVIEW with whoever knows this person best on a day to day basis. As a general rule, it is not comfortable or appropriate to ask these items of the person directly.
2. Please record the person's highest observed ability on each item.
3. Consider only what the person DOES do, NOT what the person "can" do or "could" do or "might be able to" do. We want no speculation - only observed, actual capabilities.
4. Count "typical" behavior, that is, behavior that is performed at least 75% (three fourths) of the time.
5. Count capabilities if done with VERBAL assistance, but NOT those done with PHYSICAL assistance.
6. Any item can be left blank if for some reason it is not applicable, irrelevant, or the person's capabilities are unknown.
7. On items like #1, check all that apply, count the checkmarks, and write the number of checkmarks in the space at the left.

1 Walking And Running (Check ALL that apply. With cane, crutches, brace, or walker, if used.)

- a Walks alone
 - b Walks up and down stairs alone
 - c Walks down stairs by alternating feet
 - d Runs without falling often
 - e Hops, skips or jumps
- (NONE OF THE ABOVE: ENTER 0)

2 Body Balance

- 5 Stands on "tiptoe" for ten seconds if asked
- 4 Stands on one foot for two seconds if asked
- 3 Stands without support
- 2 Stands with support
- 1 Sits without support
- 0 None of the above

3 Use Of Table Utensils

- 6 Uses knife and fork correctly and neatly
- 5 Uses table knife for cutting or spreading
- 4 Feeds self with spoon and fork - neatly
- 3 Feeds self with spoon and fork - considerable spilling
- 2 Feeds self with spoon - neatly
- 1 Feeds self with spoon - considerable spilling
- 0 Feeds self with fingers or must be fed

4 Eating In Public (Visual aids are acceptable)

- 3 Orders complete meals in restaurants
- 2 Orders simple meals like hamburgers or hot dogs
- 1 Orders soft drinks at soda fountain or canteen
- 0 Does not order food at public eating places

5 Drinking

- 3 Drinks without spilling, holds glass in one hand
- 2 Drinks from cup or glass unassisted - neatly
- 1 Drinks from cup or glass - considerable spilling
- 0 Does not drink from cup or glass

6 Toileting

- 4 Never has toilet accidents
- 3 Never has toilet accidents during the day
- _____ 2 Occasionally has toilet accidents during the day
- 1 Frequently has toilet accidents during the day
- 0 Is not toilet trained at all

7 Self-Care At Toilet (Check ALL that apply)

- ___ a Lowers pants at the toilet without help
- ___ b Sits on toilet seat without help
- _____ ___ c Uses toilet tissue appropriately
- ___ d Flushes toilet after use
- ___ e Puts on clothes without help
- ___ f Washes hands without help
- (NONE OF THE ABOVE: ENTER 0)

8 Washing Hands And Face (Check ALL that apply)

- ___ a Washes hands with soap
- ___ b Washes face with soap
- _____ ___ c Washes hands and face with water
- ___ d Dries hands and face
- (NONE OF THE ABOVE: ENTER 0)

9 Bathing

- 6 Prepares and completes bathing unaided
- 5 Washes and dries self completely
- 4 Washes and dries reasonably well with prompting
- _____ 3 Washes and dries self with help
- 2 Attempts to soap and wash self
- 1 Cooperates when being washed and dried by others
- 0 Makes no attempt to wash or dry self

10 Care Of Clothing (Check ALL that apply)

- ___ a Cleans shoes when needed
- ___ b Puts clothes in drawer or chest neatly
- _____ ___ c Puts soiled clothes in proper place for laundering/washing, without being reminded
- ___ d Hangs up clothes without being reminded
- (NONE OF THE ABOVE: ENTER 0)

11 Dressing

- 5 Completely dresses self
- 4 Completely dresses self with verbal prompting only
- 3 Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping) them with help
- _____ 2 Dresses self with help in pulling or putting on most clothes and fastening them
- 1 Cooperates when dressed, e.g., by extending arms or legs
- 0 Must be dressed completely

12 Shoes (Check ALL that apply)

- ___ a Puts on shoes correctly without assistance
- ___ b Ties shoe laces without assistance
- _____ ___ c Unties shoe laces without assistance
- ___ d Removes shoes without assistance
- (NONE OF THE ABOVE: ENTER 0)

13 Sense Of Direction

- 3 Goes several blocks from home without getting lost
- 2 Goes around the immediate home neighborhood (one block) without getting lost
- _____ 1 Goes around the inside of the home without getting lost
- 0 Demonstrates no sense of direction

14 Money Handling

- 4 Uses money with little or no assistance (e.g., assistance with budgeting is OK)
- 3 Uses money with minor assistance (e.g., checking for correct change, etc.)
- _____ 2 Uses money with some assistance (e.g., being told the correct bills or coins)
- 1 Uses money with complete assistance of staff
- 0 Does not use money

15 Purchasing

- 5 Chooses and buys all own clothing without help
- 4 Chooses and buys some clothing without help
- _____ 3 Makes minor purchases without help (e.g. snacks, drinks)
- 2 Does some shopping with slight supervision
- 1 Does some shopping with close supervision
- 0 Does no shopping

16 Writing

- 5 Writes complete lists, memos, or letters
- 4 Writes short sentences
- 3 Writes or prints more than 10 words without copying or tracing
- _____ 2 Writes or prints own name or other words without copying or tracing
- 1 Traces or copies own name or other words
- 0 Does not write, print, copy, or trace any words

17 Preverbal Expression

(Check ALL that apply)

- _____ a Is able to say (sign) at least a few words (If so, enter a "6" on the line)
 - _____ b Nods head or smiles to express happiness
 - _____ c Indicates hunger
 - _____ d Indicates wants by pointing or vocal noises
 - _____ e Expresses pleasure or anger by vocal noises
 - _____ f Chuckles or laughs when happy
- (NONE OF THE ABOVE: ENTER 0)

18 Sentences

- 3 Sometimes uses complex sentences containing "because," "but," etc.
- _____ 2 Asks questions using words such as "why," "how," "what," etc.
- 1 Speaks in simple sentences
- 0 Is non-verbal or nearly non-verbal

19 Reading

- 5 Reads books or other materials suitable for children 9 years old or older
- 4 Reads books or other materials suitable for children 7 years old
- _____ 3 Reads simple stories or comics suitable for children at a kindergarten or 1st grade level
- 2 Recognizes 10 or more words
- 1 Recognizes various signs, such as "EXIT, STOP, WOMEN, MEN" or street signs.
- 0 Recognizes no words or signs.

20 Complex Instructions (Check ALL that apply)

- _____ a Understands instructions containing prepositions, e.g., "on," "in," "behind"
 - _____ b Understands instructions in sequence, e.g., "Please do A first, and afterward, do B."
 - _____ c Understands instructions requiring a decision, e.g., "If there's any ham, make a sandwich; but if there's none, make some soup."
- (NONE OF THE ABOVE: ENTER 0)

21 Numbers

- 5 Does simple addition and/or subtraction
- 4 Counts 10 or more objects
- _____ 3 Mechanically counts aloud from 1 to 10
- 2 Counts 2 objects by saying "one, two"
- 1 Discriminates between "one" and "many"
- 0 Has no understanding of numbers

22 Time (Check ALL that apply)

- a Tells time by clock or watch correctly
 b Understands time intervals, e.g., there is 1 hour between 3:30 and 4:30
 c Understands time equivalents, e.g., "9:15" is the same as "quarter past nine"
 d Associates time on clock with various actions and events, e.g., 6:00 means dinner time
(NONE OF THE ABOVE: ENTER 0)

23 Room Cleaning

- 2 Cleans room well, e.g., sweeping, vacuuming, tidying
 1 Cleans room but not thoroughly
 0 Does not clean room at all

24 Food Preparation

- 3 Prepares an adequate complete meal (may use canned or frozen foods)
 2 Mixes and cooks simple foods, e.g., fries eggs, makes pancakes, cooks TV dinner, heats can of soup
 1 Prepares simple foods requiring no mixing or cooking, e.g., sandwiches, cold cereal, etc.
 0 Does not prepare food at all

25 Table Clearing

- 2 Clears table of breakable dishes and glassware
 1 Clears table of unbreakable dishes and silverware
 0 Does not clear table at all

26 Job Complexity

- 2 Employment of any kind (school if school age)
 1 In pre-vocational training, in adult day activities, or retired
 0 Performs no work

27 Initiative

- 3 Initiates most of own activities
 2 Initiates some of own activities
 1 Will engage in activities only if assigned or directed
 0 Will not engage in assigned activities

28 Attention

- 4 Will pay attention to purposeful activities for more than 20 minutes
 3 Will pay attention to purposeful activities for about 15 minutes
 2 Will pay attention to purposeful activities for about 10 minutes
 1 Will pay attention to purposeful activities for about 5 minutes
 0 Will not pay attention to purposeful activities for as long as 5 minutes

29 Personal Belongings

- 3 Very dependable, always takes care of belongings
 2 Usually dependable, usually takes care of belongings
 1 Unreliable, seldom takes care of belongings
 0 Not responsible at all, does not take care of belongings

30 Awareness Of Others (Check ALL that apply)

- a Recognizes own family
 b Recognizes people other than family (If "b" is checked, also check "a")
 c Has information about others, e.g., relation to self, job, address, name
 d Knows the names of people close to him/her, e.g., in neighborhood, at home or day program
 e Knows the names of people not regularly encountered
(NONE OF THE ABOVE: ENTER 0)

31 Interaction With Others

- 3 Interacts with others in group games
 2 Interacts with others for at least a short period of time, e.g. showing or offering toys, clothing or objects
 1 Interacts with others imitatively with little interaction
 0 Does not interact in a socially acceptable manner

32 Participation In Group Activities

- 3 Initiates group activities at least some of the time (leader and/or organizer)
- 2 Participates in group activities spontaneously and eagerly (active participant)
- _____ 1 Participates in group activities if encouraged to do so (passive participant)
- 0 Does not participate in group activities (unless physically guided)

Orientation Toward Productive Activities Scale

(Job, Day Program, Household Chores, Shopping, Volunteering, School Or Other Education, Hobbies, Exercise Programs, Etc.)

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Instructions: These items usually have to be asked to informants who do not observe the person at his/her job, day program, or school on a daily basis. The items, however, are designed so that residential staff can answer them on the basis of the productive activities they have observed, such as hobbies, shopping, household chores, and so on. Also, the items can be completed for school children.

1. Motivation for Productive Activities

- 5 Enthusiastic about productive activities
- 4 Strong motivation for productive activities
- 3 Moderate motivation for productive activities
- _____ 2 Slight motivation for productive activities
- 1 Needs constant support and/or encouragement for productive activities
- 0 No evidence of motivation, willingness, or interest in productive activities

2. Getting Up

- 5 Completely independent and reliable about getting up on time
- 4 Awakens by self, reliably, but not always on time
- 3 Awakens by self, but not reliably
- _____ 2 Cooperative about getting up, but must be awakened
- 1 Considerable difficulty with getting up in the morning
- 0 Completely dependent, must be awakened and assisted

3. Getting to Productive Activities

- 4 Gets to productive activities independently (This can mean catching a specialized bus or van without help)
- 3 Gets to productive activities with minor assistance such as verbal reminders
- _____ 2 Partly dependent on others, but does some part of the travel independently
- 1 Largely dependent on others, but does assist with parts of the routine
- 0 Completely dependent on others to get to productive activities

4. Promptness at Productive Activities

- 5 Never or almost never late arriving, or returning from an outing
- 4 Rarely late
- 3 Sometimes late
- _____ 2 Often late
- 1 Usually late arriving, or returning from an outing
- 0 Not aware of time or promptness as an issue; dependent on support persons

5. Attendance at Productive Activities

- 5 Always attends if able
- 4 Almost always attends if able
- 3 Usually attends if able
- _____ 2 Sometimes does not attend although able
- 1 Often does not attend although able
- 0 Will not attend willingly

6. Amount of Supervision and Support Needed During Productive Activities

- 5 Very independent during productive activities, no need for supervision
- 4 Rarely needs supervision or support
- 3 Needs occasional supervision and support
- _____ 2 Needs frequent supervision and support
- 1 Needs constant supervision and support as part of a group
- 0 Needs constant one-on-one supervision and support

7. Working With Others

- 4 Works very well with others, creates positive work relationships
- 3 Works well with others
- _____ 2 Works fairly well with others
- 1 Has considerable difficulty working with others
- 0 Does not work with others

8. Organization During Productive Activities

- 4 Organizes productive activities very well without supervision
- 3 Organizes productive activities fairly well without supervision
- _____ 2 Organizes productive activities somewhat with general supervision
- 1 Organizes productive activities only with close supervision
- 0 No organization of work or other productive activities

9. Following Safety Rules and Regulations During Productive Activities

- 4 Very careful about safety rules and regulations, without supervision
- 3 Complies with safety rules and regulations with minimal or no supervision
- _____ 2 Complies with safety rules and regulations with general supervision
- 1 Complies with safety rules and regulations only with close supervision
- 0 Shows no awareness of, nor compliance with, safety rules and regulations

10. Quality of Productive Activities

- 5 Quality is usually excellent
- 4 Quality is usually very good
- 3 Quality is usually good
- _____ 2 Quality is usually fair
- 1 Quality is usually poor
- 0 No evidence of attention to, or awareness of, quality

11. Keeping an Outside-the-Home Productive Role (e.g. school, job, volunteer work, day program)

- 6 Has a long term productive role with stability
- 5 Has kept a productive role for a long period, over a year
- 4 Has kept a productive role for as long as a year
- _____ 3 Has kept a productive role for as long as 6 months
- 2 Has kept a productive role for as long as a month
- 1 Usually quits or is asked to leave after a few days or weeks
- 0 Does not keep a productive role, or has had none

12. Advancement (grade level advance, promotions, raises, titles, better job or role)

- 5 Has advanced three or more times in the past year
- 4 Has advanced twice in the past year
- 3 Has advanced once in the past year
- _____ 2 Has advance more than once, but not in the past year
- 1 Has advanced once, but not in the past year
- 0 Has never advanced at day program or job

Adjustment And Challenges Scale: During The Past 4 Weeks

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This scale should be asked of whoever knows the person best on a day-to-day basis.

Problem Severity: 0=None 1=Mild 2=Moderate 3=Major 4=Extreme		Adjustment and Challenge Area
	1	Assaulting Others
	2	Damaging Property
	3	Hyperactivity/Mania
	4	Inappropriate, Illegal, Or Dangerous Sexuality
	5	Lying
	6	Running Away
	7	Screams/Cries/Yells Inappropriately
	8	Setting Fires
	9	Stealing
	10	Threatening Others
	11	Anxiety/Panic
	12	Depressive Symptoms
	13	Eating Disorders
	14	Hallucinations/Delusions
	15	Poor Grooming/Cleanliness
	16	Self-Injury
	17	Social Withdrawal
	18	Substance Abuse
	19	Suicidal Actions, Tendencies, Thoughts
	20	Unusual/Repetitive/Stereotyped Behaviors

Individual Budget Information

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1. Does this person have a single unified individual budget of public funds supporting him/her?
 0=No (Go on to Item 2)
 _____ 1=Yes (Skip to Item 6)
 9=Don't Know (Go on to Item 2)

IF THIS PERSON DOES NOT NOW HAVE AN INDIVIDUAL BUDGET:

2. About how much per year in public funds are spent for this person's residential supports?
 _____ dollars per year (exclude SSI, SSDI, or other public assistance funds)
3. About how much per year does this person receive through SSI, SSDI, or other public assistance programs?
 _____ dollars per year
4. About how much per year in public funds are spent for this person's day program, school, or employment?
 _____ dollars per year
5. About how much per year in public funds are spent for other supports for this person?
 _____ dollars per year

SKIP THE REMAINDER OF THIS SECTION, IF THE PERSON DOES NOT NOW HAVE AN INDIVIDUAL BUDGET, AND THE ABOVE 4 ITEMS WERE ANSWERED.

ANSWER THE FOLLOWING ITEMS ONLY IF THE PERSON CURRENTLY HAS AN INDIVIDUAL BUDGET.

6. About how long has this person had an individual budget?
 _____ months
7. About how much is in the person's individual budget annually?
 _____ dollars per year (leave blank if unknown)
8. Try to obtain rough estimates of how these individual budget funds are spent. If the person is living in a group situation, try to figure out how much this person's supports costs (often you simply divide by the number of people). Sometimes, this information simply won't be available on site. Make one attempt to get estimates, and if you can't, then leave this matrix blank and move on.

	8A. Housing (including rent, mortgage, utilities, food, household supplies, etc.)
	8B. Personal support in the home (staff, personal care attendants, home health aides, support coordinators, etc.)
	8C. Transportation of all kinds
	8D. Supported work, education tuition, adult day activity, community experience program
	8E. Therapies (psychological, physical, occupational)
	8F. Recreation, entertainment, vacations, buying leisure items such as televisions, stereos, exercise equipment, or luxuries
	8G. Other

9. To what extent does this person (and/or circle) directly control the use of his/her individual budget?

- 1 Not at all
- 2 Advises a paid staff person, who also uses their own discretion as needed.
- 3 Advises a family member, who also uses their own discretion as needed.
- _____ 4 Has a guardian who makes these decisions.
- 5 Shares direct control over use of individual budget with another person
- 6 Has complete control over the use of their individual budget
- 9 Not applicable

10. In what ways does this person (with unpaid supports if needed) control his/her individual budget?

0=No

1=Yes

- _____ 10A. Took part in the original development of the budget
- _____ 10B. Keeps track of how budget is being spent
- _____ 10C. Decides how much personal assistance s/he wants each week.
- _____ 10D. Signs and/or authorizes payments to providers of supports.
- _____ 10E. Decides how their individual budget will be modified, with or without assistance.
- _____ 10F. Selects and/or directs a fiscal intermediary to distribute pay or other resources
- _____ 10G. Other (Specify, such as has a PASS approved, or other method of exercising control.)

11. Did the person choose whether or not he/she would control the individual budget? (Answer yes if the person received unpaid support to make this decision.)?

0 No

_____ 1 Yes (by him/herself, OR with unpaid support if applicable)

9 Not Applicable

12. Does the person have a fiscal intermediary to assist in handling all or some of the individual budget?

0 No

_____ 1 Yes

9 Don't Know

13. Did the person choose his/her fiscal intermediary?

1 No. Agency chose fiscal Intermediary.

2 No. Relative or guardian made this choice without input from the person.

_____ 3 Partially, with help from paid agency staff

4 Partially, with help from unpaid relatives friends or guardians

5 Yes.

9 Not Applicable (Person is not capable of making this choice)

14. Please BRIEFLY describe who acts as fiscal intermediaries, and what function(s) they perform on the person's behalf., e.g., payroll for support personnel.

Individual Planning and Supports (Past 12 Months Only)

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1. Does the person have an Individual Plan?

0 No (if No, skip this section)

1 Yes, but no copy of it is kept here

_____ 2 Yes, and normally a copy would be here, but is not now

3 Yes, and a copy of it is here

2. What is the plan called? If there is more than one, please name the one that is **most useful, and most familiar to the focus person and his/her support network** (relatives, staff, case managers, etc.). The Plan may be an IEP for school students.

3. Elements of the Planning Process

	1=Not at all 2=Somewhat 3=Half 4=Mostly 5=Completely 9=Don't know, Not applicable
A	How were you involved in the planning process for this person? (If Not at all, skip the rest of this table.)
B	Does the planning process make strong efforts to understand the focus person's long term dreams? (As opposed to short term goals set by others.)
C	Does the planning process emphasize building a network of supports from informal, unpaid, or general community sources?
D	Are the meetings comfortable and relaxed for the focus person? (As opposed to formal and "official.")
E	Are planning sessions scheduled as needed? (As opposed to a regular set schedule, such as annually.)
F	Is the planning process defined or regulated by a set of standards, licensing requirements, rules, or laws, or regulations?
G	Does the planning process encourage creativity, new ideas, different ways of thinking?
H	Does the planning process allow for conflicts and disagreements, and try to resolve them?
I	Is the planning process flexible, allowing for changes in approach when things do not work?
J	Does the person have ultimate authority? (Could he or she overrule the entire group on an issue, within safety limits?)
K	Did the planning process emphasize cooperation among all participants? (As opposed to professional authority.)
L	Does the planning process emphasize the person's relationships? (As opposed to emphasizing skill development, or behavior, or services.)
M	Does the planning process take money into consideration? (Does the group discuss what supports cost, and what alternatives there are?)
N	Does the planning group have control over the resources (money) devoted to supporting the focus person?
O	Do the unpaid group members have the real power? (As opposed to paid staff and professionals.)
P	Do you consider this plan to be "person-centered"?

4 PLAN DATE: When was this plan last approved and/or signed, or otherwise put into effect?

_____/_____
 Month Year

5. PLANNING MEETINGS: About how many times did the planning group get together in the past year to create this plan?

_____ planning meetings in the past year?

6. APPROXIMATE AVERAGE LENGTH OF A PLANNING MEETING:

_____ hours per session

7. NUMBER OF PLANNING PARTICIPANTS: How many people participated/are participating in the person's planning efforts right now?

_____ members

8. PLEASE CATEGORIZE THESE CURRENT **PLANNING PARTICIPANTS**:

Number of Paid Personnel	Number of Unpaid Relatives	Number of Unpaid Non-Relatives	
8A _____	8B _____	8C _____	Number invited by the person and/or the person's circle of friends
8D _____	8E _____	8F _____	Number not invited by the person and/or the person's circle of friends

9. FACILITATOR: Who usually facilitated at these planning sessions?

- 1 Friend
- 2 Family member
- 3 Case Manager/Support Coordinator/Service Coordinator/Personal Agent
- 4 Paid Staff Member
- _____ 5 Professional (e.g. psychologist, psychiatrist, special educator, therapist)
- 6 The person in combination with a co-facilitator
- 7 The person
- 8 Facilitator varied, rotated, there was no "usual" facilitator
- 9 Other _____

10. LOCATION: Where were these formal meeting usually held?

- 1 Agency Office
- 2 Person's Home
- _____ 3 Relative's Home
- 4 Friend's Home
- 5 Restaurant(s)
- 6 School
- 7 Varied locations decided on by the focal person or the group
- 9 Other (**Specify**)

11. PRESENCE AT PLANNING PROCESS: Was the person present at the planning sessions?

0 No

_____ 1 No, person chose not to be present

2 Yes, person was present for a small part of the process

3 Yes, person was present for most or all of the process

12. PARTICIPATION IN PLANNING PROCESS: Did the person participate in the planning process?

0 No, person was not able to participate

_____ 1 No, person chose not to participate

2 Yes, minimally

3 Yes, actively

13. CASE MANAGER/SUPPORTS COORDINATOR COMMUNICATION WITH PERSON: Approximately how many times **in the past 30 days** did the Case Manager/Supports Coordinator contact (including visits) the person?

_____ Number of times

14. PLAN'S USEFULNESS: How useful is the person's Plan to you and other helpers in day to day interactions with him/her? (This item is to be answered by whoever knows the person best on a day to day basis.)

1 Not At All Useful - The Plan is pretty much just a piece of paper, and helpers rarely look at it

2 Not Very Useful

_____ 3 Somewhat Useful

4 Very Useful

5 Extremely Useful - It is the primary source of guidance for day-to-day interactions with this person

9 Don't know or not applicable

Individual Plan Summary

The summary on the following page is intended to get at what is in the person's Individual Plan. If there is a Person Centered Plan, use that plan.

Write each need, desire, preference, goal, or objective very briefly, then proceed to describe each one across the columns. Rank order the goals in their importance, tell how much each is being addressed by paid and unpaid supports, and the amount of progress thus far made toward each goal.

General instructions:

- Rank ordering the importance of the goals can come from the plan, from your own knowledge of the person, from the opinion of whoever knows the person best, or from the focus person. Rank as many as possible, even if they can't all be ranked.
- Level of Paid Supports and Level of Unpaid Supports could both be "Highest," at least in theory. They are meant to be independent of one another. If one is high, the other one does not have to be low.
- If the plan contains more than 5 major needs, desires, or preference, try to restrict this summary to the most important 5.
- For progress seen in the past year, again use records, your own knowledge, and/or the opinion of whoever knows the person best on a day to day basis.
- Finally, where a question just can't be answered, enter 99.

Individual Plan Summary (Top 5 Goals)

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<p>Short Description of Top 5 Goals in the Plan Use as few words as possible, please.</p> <p>Goals might be called needs, desires, preferences, non-negotiables, or objectives. Whatever the terminology, we are trying to get at the 5 most important things that are being worked on right now.</p>	<p>Rank Order of the Importance of This Item</p> <p>1=First 2=Second 3=Third 4=Fourth 5=Fifth etc. 99=D/K</p>	<p>Level of Paid Supports for This Item</p> <p>1=None 2=Minor 3=Moderate 4=Intense 5=Highest 99=D/K</p>	<p>Level of Unpaid Supports for This Item</p> <p>1=None 2=Minor 3=Moderate 4=Intense 5=Highest 99=D/K</p>	<p>Has There Been Any Progress Toward This Item in the Past Year?</p> <p>-2=Major Loss -1=Some Loss 0=No change +1=Some Gain +2=Major Gain 99=D/K</p>
A				
B				
C				
D				
E				

“Traditional” Services/Supports

Provided Via the Home (Residential Setting), OR the Job or Day Program

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INSTRUCTIONS

- First, find out whether each service is in any way mentioned, prescribed, or required in this person’s Person Centered Plan **OR** Support Plan **OR** any other formal written plan.
- Then get an estimate of how many hours per week are devoted to this service; **only a rough estimate!!!**
- If the service is not received every week, make notes in the margin and figure out **average** hours per week later.
- It’s possible to have services that are in the plan, but are not now being delivered (example: goal was achieved already) --- in which case, enter “1” in the first column, and “0” in the second. Or, if services are being delivered that are not in the Plan, enter “0” and “1.”

Is This Service Called for in Any Formal Written Plan?	ROUGHLY How Many Hours Per Week Does the Person Actually Receive? HOURS/WEEK (0 if None)
0=No 1=Yes	

1A _____	1B _____	1 BASIC SELF-CARE SKILLS Teaching, not just helping; including hygiene, dressing, eating, domestic skills
2A _____	2B _____	2 COMMUNITY SKILLS Formal programs to teach shopping, transportation, handling emergencies, etc.
3A _____	3B _____	3 APPROPRIATE SOCIAL BEHAVIOR Manners, interpersonal skills, etc.
4A _____	4B _____	4 COGNITIVE SKILLS Letters, numbers, shapes, colors, reading, writing, arithmetic
5A _____	5B _____	5 OCCUPATIONAL THERAPY Delivered, designed, or supervised by an Occupational Therapist
6A _____	6B _____	6 PHYSICAL THERAPY Delivered, designed, or supervised by a Physical Therapist
7A _____	7B _____	7 COMMUNICATION, SPEECH, & HEARING THERAPY Formal programs designed to improve communication abilities (devices included)
8A _____	8B _____	8 RECREATION Learning ways to use leisure time
9A _____	9B _____	9 PSYCHOTHERAPY OR COUNSELING Delivered directly by a trained therapist
10A _____	10B _____	10 SEXUALITY EDUCATION, OR COUNSELING Teaching person how to make safe and rewarding choices
11A _____	11B _____	11 SPECIALIZED TRANSPORTATION PROGRAM Contracted transportation service, not including paratransit
12A _____	12B _____	12 PERSONAL CARE ATTENDANT OR AIDE Providing help with physical needs
13A _____	13B *****	13 PROGRAMS TO REDUCE CHALLENGING BEHAVIOR Systematic reinforcement programs of any kind * Note: Amount of time is probably not meaningful in this category, because such programs are constant and ongoing.

Weekday Routine and Activities

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1. WEEKDAY ROUTINE - AVERAGE WEEKDAY (Using decimals or fractions is fine.)

1A		Hours per day in bed (asleep or resting)
1B		Hours per day napping
1C		Hours awake on a weekday
	XXXX	(The three figures above should add up to 24 hours)
1D		Hours of work or any regular day activity
1E		Hours spent traveling to work or any regular day activity
1G		Hours spent in the home
1H		Hours spent on outings (shopping, visiting, errands, recreation, etc.)
	XXXX	(The four figures above should add up to the total hours the person is awake)

Daytime Activity Program, Work, and School

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2. HOURS PER WEEK OF DAYTIME ACTIVITIES, JOB, AND/OR SCHOOL:

- Please enter the number of hours per week for each activity, 0 (zero) if none in the category.
- To make specific answers easier, refer to “last week,” or, if necessary, a “typical week.”

<u># Hours</u>	<u>Type of Day Activity</u>	
_____	2A	Self-Employed: Has His/Her Own Business
_____	2B	Regular Job (Competitive Employment)
_____	2C1	Supported Employment, Individual Placement Model
_____	2C2	Supported Employment, Enclave Model
_____	2C3	Supported Employment, Mobile Work Crew
_____	2D	Sheltered Employment or Workshop Employment (segregated)
_____	2E	Pre-Vocational Program or Vocational Rehabilitation Program
_____	2F	Day Habilitation Program (Adult Day Program, Non-Vocational Day Program)
_____	2G	Senior Citizen Program
_____	2H	Partial Hospitalization Program - Mental Health Oriented
_____	2I	Volunteer Work
_____	2J	Public School (Regular School Building and/or classroom)
_____	2K	Public School (Separate Building or 'Center Based')
_____	2L	Private School (Regular School Building and/or classroom)
_____	2M	Private School (Separate Building or 'Center Based')
_____	2N	Adult Education - GED, Adult Ed, Trade School, etc.
_____	2O	Community Experience
_____	2P	Other _____
_____	2R	TOTAL _____

3. IF DAY PROGRAM HOURS TOTAL TO ZERO, PLEASE EXPLAIN WHY (e.g., retired)

4. ABOUT HOW LONG HAS THE PERSON BEEN IN THE PRIMARY DAY ACTIVITY?

(Primary meaning the most hours per week.)

_____ years _____ months

5. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF CO-WORKERS OR PEERS WHO DO NOT HAVE DISABILITIES? (Do not count during transportation.)

1 None or nearly none

2 Less than half the time

_____ 3 About half the time

4 More than half the time

5 All or nearly all

6. DURING DAY ACTIVITIES, WORK, OR SCHOOL, HOW MUCH TIME DOES THE PERSON SPEND IN THE PRESENCE OF THE **GENERAL PUBLIC**? (Do not count during transportation.)

1 None or nearly none

2 Less than half the time

_____ 3 About half the time

4 More than half the time

5 All or nearly all

7. EARNINGS: ABOUT HOW MUCH MONEY DOES THIS PERSON EARN IN AN AVERAGE WEEK? (Accept per hour, biweekly, per month, or annual gross, and make notes --- then convert to dollars per week later if necessary.)

_____ Dollars per week

Connections with Family and Friends

Who is this person's closest relative or guardian? We will send a mail survey to this individual.

0. Does this person have relative(s) who might respond to a survey about the person's well-being?
1. No known relatives to survey
 - _____ 2. Yes, relatives are known, but **THEY WANT NO CONTACT**
(We will NOT mail a survey to them.)
 3. Yes

**BE SURE TO GET COMPLETE ADDRESSES, INCLUDING ZIP CODES.
PLEASE COMPLETE THIS ADDRESS EVEN IF THE PERSON LIVES WITH THE
RELATIVE. (Even if the relative's address is the same as the person's.)**

1. _____
Name(s) of Relative or Guardian
2. _____
Relationship to the Person
3. _____
Complete Mailing Address, Including Apartment #, Line 1
4. _____
Complete Mailing Address, Including Apartment #, Line 2
5. _____ 6. _____ 7. _____
City or Town State Zip Code
8. _____ 9. _____
Telephone Number Primary Language, if not English

10. Involvement of Relative(s): About how often do **any** relatives have the following kinds of contact with this person? (Accept times per week, or per month, and convert to approximate number of times per year.) **(Enter N/A if the person lives with a relative.)**

About how many times in the
past year? (Zero if none)

- _____ 10a. Telephone calls (including talking with staff)
- _____ 10b. Mail
- _____ 10c. Relative visits person here at this home
- _____ 10d. Person goes out with relative(s)
- _____ 10e. Program Planning Meetings
- _____ 10f. Consent for medical care

11. **Number Of Friends:** About how many people in this person's life would you describe as friends? Do not count mere acquaintances (people one might say "Hi" to, or wave to, but with whom there is no other interaction). Friends might include housemates, co-workers, schoolmates, other people with disabilities served by the residential or day program agency, direct care workers, case managers, support coordinators, therapists, churchgoers, neighbors, merchants (workers in any commercial store), letter carriers, law officers, advocates, guardians, etc.

_____ friends

Close Friends Scale

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This table is intended to get at the types and characteristics of a few of the person's closest friendships.

- A "close friend" is anyone the person (or whoever knows the person best) defines that way.
- If there are fewer than 5 close friends, just describe however many there are.
- If there are close friendships with more than 5 people, please try to count only the closest 5.
- A relative can be a friend, but contacts with relatives have already been described above, so only include a relative here if the person or the respondent feels it is important to do so.
- This scale may be left empty, if the person has no close friends; please indicate this with a large "X."

Initials or code:	Relationship (Present or Former) 1=Relative 2=Staff of home 3=Staff of day program, school, or job 4=Other paid (Case manager, nurse, etc.) 5=Housemate 6=Co-worker or schoolmate 7=Neighbor 8=Merchant 9=Other	Gender of this friend 1=Female 2=Male	Does this friend have a disability? 0=No 1=Yes 9=D/K	About how long has the person known this friend? (<u>Years</u> - use fractions and decimals if needed, as in 2.5 years, or 2 ½ years) (999=D/K)	Is this friend involved in planning meetings, PCP, or circles? 0=No 1=Yes, minor 2=Yes, moderate 3=Yes, major	About how many times has the person had contact with this friend, in the past four weeks (28 days)? For people seen several times every day, such as staff of the home, just enter 28.
1						
2						
3						
4						
5						

Decision Control Inventory 2: For People Living With Family or Friends

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Ask the respondent to say who actually makes decisions in each area as shown, from 0 to 10. If decisions are made entirely by RELATIVES/FRIENDS/ADVOCATES (usually unpaid, but sometimes formerly unpaid who are now being paid via self-determination), enter "0" for that area. If decisions are made entirely by the FOCUS PERSON, enter "10." If decisions are equally shared, enter "5." Items can be left blank. Next, rate each area for "How Important" it is for the focus person to have control in each area.

WHO MAKES DECISIONS?

0---1---2---3---4---5---6---7---8---9---10

Relatives/
Friends/Advocates/
Circles

Focus Person

HOW IMPORTANT IS IT TO THIS PERSON TO HAVE CONTROL IN EACH AREA?

0---1---2---3---4---5---6---7---8---9---10

Completely
Unimportant

Extremely
Important

WHO			IMP.
_____	1P	What foods to buy for the home when shopping	_____ 1I
_____	2P	What to have for breakfast	_____ 2I
_____	3P	What to have for dinner	_____ 3I
_____	4P	Choosing restaurants when eating out	_____ 4I
		CLOTHES AND GROOMING	
_____	5P	What clothes to buy in store	_____ 5I
_____	6P	What clothes to wear on weekdays	_____ 6I
_____	7P	What clothes to wear on weekends	_____ 7I
_____	8P	Time and frequency of bathing or showering	_____ 8I
		SLEEP AND WAKING	
_____	9P	When to go to bed on weekdays	_____ 9I
_____	10P	When to go to bed on weekends	_____ 10I
_____	11P	When to get up on weekends	_____ 11I
_____	12P	Taking naps in evenings and on weekends	_____ 12I
		RECREATION	
_____	13P	Choice of places to go	_____ 13I
_____	14P	What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.	_____ 14I
_____	15P	Visiting with friends outside the person's residence	_____ 15I
_____	16P	Choosing to <u>decline</u> to take part in group activities	_____ 16I
_____	17P	Who goes with you on outings?	_____ 17I
_____	18P	Who you hang out with in and out of the home?	_____ 18I
		SUPPORT AGENCIES AND STAFF	
_____	19P	Choice of which service agency works with person	_____ 19I
_____	20P	Choice of Case Manager	_____ 20I
_____	21P	Choice of agency's support persons/staff (N/A if family)	_____ 21I
_____	22P	Choice of support personnel: option to hire and fire support personnel	_____ 22I
		ECONOMIC RESOURCES	
_____	23P	What to do with personal funds	_____ 23I
_____	24P	How to spend residential funds	_____ 24I
_____	25P	How to spend day activity funds	_____ 25I
		HOME	
_____	26P	Choice of house or apartment	_____ 26I
_____	27P	Choice of people to live with	_____ 27I
_____	28P	Choice of furnishings and decorations in the home	_____ 28I
		WORK OR OTHER DAY ACTIVITIES	
_____	29P	Type of work or day program	_____ 29I
_____	30P	Amount of time spent working or at day program	_____ 30I
_____	31P	Type of transportation to and from day program or job	_____ 31I
		OTHER	
_____	32P	Express affection, including sexual	_____ 32I
_____	33P	"Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.	_____ 33I
_____	34P	Whether to have pet(s) in the home	_____ 34I
_____	35P	When, where, and how to worship	_____ 35I

Integrative Activities During the Past Month

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ABOUT HOW MANY TIMES did this person do each of the following in the PAST MONTH? ONLY COUNT ACTIVITIES WHEN THE PERSON WAS IN THE PRESENCE OF NON-DISABLED CITIZENS. (**Rough estimates are fine.** If the past month was not typical, ask about the average month during the past year. Write DK if "Don't Know.")

- _____ 1. Visit with close friends, relatives or neighbors
- _____ 2. Visit a grocery store
- _____ 3. Go to a restaurant
- _____ 4. Go to church or synagogue
- _____ 5. Go to a shopping center, mall or other retail store to shop
- _____ 6. Go to bars, taverns, etc.
- _____ 7. Go to a bank
- _____ 8. Go to a movie
- _____ 9. Go to a park or playground
- _____ 10. Go to a theater or cultural event (including local school & club events)
- _____ 11. Go to a post office
- _____ 12. Go to a library
- _____ 13. Go to a sports event
- _____ 14. Go to a health or exercise club, spa, or center
- _____ 15. Use public transportation (May be marked "N/A")
- _____ 16. Other kinds of "getting out" not listed above

17. **TRANSPORTATION TYPES:** Which of these kinds of transportation has this person used in the past month? Please mark "0" for those that were not used, and "1" for those that were used.

0=Not used in the past month

1=Used in the past month

- _____ 17A Agency car or van
- _____ 17B Car or van assigned to this home
- _____ 17C Family member's car or van
- _____ 17D Staff member's car or van
- _____ 17E Friend's car or van
- _____ 17F Person's own car or van
- _____ 17G Agency bus
- _____ 17H Taxicab
- _____ 17I Public transportation (bus)
- _____ 17J Paratransit (specialized public transportation for people with disabilities)

18. **ACCESS TO TRANSPORTATION:** If this person wanted to go somewhere on the spur of the moment (beyond walking distance), how many times out of 10 would he/she be able to? If this person does not communicate such wants, phrase the question as "If someone unpaid wanted this person to be able to go somewhere on the spur of the moment" Count only trips that are within 1 hour of home.

_____ times out of 10

Health Information

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1. GENERAL HEALTH: In general, how is this person's health?

1 Very Poor

2 Poor

_____ 3 Fair

4 Good

5 Excellent

2. ILLNESS IN PAST 28 DAYS:

_____ Number of days of restricted activity because of illness

3. DENTIST VISITS: About how many times has the person been to the dentist in the past year?

_____ 3A Total Visits

_____ 3B Number of times for exams, cleaning, and general preventive work

_____ 3C Number of times for major work, surgery, or emergency situations

4. DOCTOR VISITS: About how many times has the person been seen by a doctor in the past year?

_____ 4A Total times seen by doctors in past year (**approximate**)

_____ 4B About how many visits were for acute illness?

_____ 4C About how many visits were for normal preventive care?

_____ 4D About how many visits to an Emergency Room?

_____ 4E About how many visits were to specialists?

5. What were the kinds of specialists most often seen?

5A _____

5B _____

5C _____

6. What was the reason for the most recent Emergency Room visit?

7. HOSPITAL ADMISSIONS: How many times in the past year has the person been admitted to a hospital for any reason?

8. What was the reason for the most recent hospital admission?

9. "MEDICAL HOME": Does this person have a clearly identified primary care physician who is responsible for primary care and coordination?

0 No

_____ 1 Yes

10. How is this person's health care paid for? (Enter a "1" for all that apply.)

0=No

1=Yes

- _____ 10A Medicaid, fee for service
- _____ 10B Medicaid, in some variety of managed care, HMO, HSO, HIO, MCO, MSO, PSRO, etc.
- _____ 10C Medicare
- _____ 10D Private health insurance
- _____ 10E Private payment for services
- _____ 10F Other, describe

11. **PRESCRIBED DAILY MEDICATIONS:** Please PRINT the name of each PRESCRIBED medication that the person is receiving. Under PURPOSE, use these codes:

- 1 = Control of Psychiatric Symptoms (Neuroleptics, psychotropics, antipsychotics; commonly Mellaril, Haldol, etc.)
- 2 = Behavior Control, Calming (Major and minor tranquilizers)
- 3 = Sleep (Medications to induce or prolong sleep)
- 4 = Antidepressant (To reduce depression, withdrawal; to elevate mood)
- 5 = Seizure Control
- 6 = Digestive, Stomach, Bowel (For heartburn, ulcer, laxative, etc.)
- 7 = Chronic Health Condition (For heart, hypertension, diabetes, etc.)
- 8 = Nutritional Supplements (Vitamins, minerals, special supplements)
- 9 = Other
- 99 = Don't Know

NAMES OF PRESCRIBED MEDICATIONS	PURPOSE
11A	11B
11C	11D
11E	11F
11G	11H
11I	11J
11K	11L
11M	11N
11O	11P
11Q	11R

11R. How many errors in the administration of medications occurred in the past month? Do not include errors in documentation.

_____ medication errors other than documentation (enter zero if none)

11S. Please describe the most recent medication error, if any.

12. CURRENT WEIGHT STATUS:

- 1 Seriously Underweight
- 2 Significantly Underweight
- _____ 3 At or Near Weight Ideal for Height and Build
- 4 Significantly Overweight
- 5 Seriously Overweight

13. WEIGHT GAIN OR LOSS: Has this person gained or lost weight within the past year?

- 1 Significant Gain (more than 10%)
- 2 Slight Gain
- _____ 3 No Change
- 4 Slight Loss
- 5 Significant Loss (more than 10%)

14. Who has evaluated the SIGNIFICANT weight gain or loss? (Enter "1" for all that apply.)

- _____ 14A No Evaluation Has Been Done
- _____ 14B Primary Physician
- _____ 14C Nurse
- _____ 14D Dietitian
- _____ 14E Other (specify: _____)
- _____ 14F None needed -- no SIGNIFICANT weight gain or loss

15. Describe the process of finding medical care for this person:

- 1 Very Difficult
- 2 Difficult
- _____ 3 About Average
- 4 Easy
- 5 Very Easy

16. Please describe the relationship between this person and the primary care physician.

- 1 Very negative (such as cold, uncaring, fearful, etc.)
- 2 Negative
- _____ 3 Neutral
- 4 Positive
- 5 Very positive (such as pleasant, warm, patient, gentle, caring)

17. RESPONDENT OPINION: Overall, how good is this person's health care?

- 1 Very Poor
- 2 Poor
- _____ 3 Fair
- 4 Good
- 5 Excellent

18. INJURIES: How many injuries requiring medical attention has this person had in the past year?

_____ # of injuries

19. ABUSE or NEGLECT: How many events of abuse, mistreatment, or neglect have been alleged about this person in the past year?

_____ # of allegations

20. RESTRICTIVE PROCEDURES: Approximately how many times have restrictive procedures been used with this person in the past year?

** _____ # of times restrictive procedures used

Questions To Be Asked of the Respondent Who Knows the Person Best

(Paid Personnel Only)

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1. Do you work here part time or full time?

1 Part Time

_____ 2 Full Time

2. How long have you been working with this person?

_____ Years and _____ Months

3. How long have you been working in this field (mental retardation, developmental disabilities, mental health)?

_____ Years and _____ Months

4 What do you think are the things most important to this person's happiness? (Up to three things.)

4A _____

4B _____

4C _____

5. What things make this person the most unhappy? (Up to three things.)

5A _____

5B _____

5C _____

6. If you could have one wish granted for this person, what would you wish for?

7. Before today, how much did you know about the cost of supporting this person?

1=Nothing at all

2=Very little

_____ 3=Some

4=A lot

5=Everything or almost everything

8. How do you feel about the money society spends to support this person?

1=Much too little

2=Too little

_____ 3=OK

4=Too much

5=Much too much

Qualities of Work Life, Before Self-Determination, and Now

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OPTIONAL: For Case Managers or Support Coordinators

(If this PLQ is being completed by a Case Manager or Support Coordinator, please complete this page; Otherwise, skip.)

(If not yet involved in self-determination, “Before” should be changed to “A Year Ago.”)

0	1	2	3	4	5	6	7	8	9	10
Extremely										Extremely
Poor										Good

Before (or a year ago)		Now		
	1A		1B	Your ability to get things done on time
	2A		2B	Understanding what your job is
	3A		3B	Stability of your job
	4A		4B	How much you like your job
	5A		5B	Your belief that you are helping people in your job
	6A		6B	Your relationships with co-workers
	7A		7B	Your relationship with THIS person (consumer)
	8A		8B	Your relationships with recipients' families
	9A		9B	Your relationships with your agency's managers
	10A		10B	Freedom from bad rules, regulations, and red tape
	11A		11B	Your participation in the individual planning process
	12A		12B	Your belief in the self-determination idea

13. How many people are on your “caseload”?

14. How many of those people are now involved in self-determination?

Quality of Life Changes

(To Be Answered by the Person or Whoever Knows the Person Best)

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Ask the person to rate the qualities of his/her own life “BEFORE” and “NOW.” For the Self-Determination Project, “BEFORE” means before this person became involved in Self-Determination. If the person has not yet begun, or has just begun, involvement, use “A YEAR AGO” in place of “BEFORE.” **If the person can't answer, accept answers from whoever knows the person best.**

BEFORE 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		NOW 1 Very Bad 2 Bad 3 OK 4 Good 5 Very Good		
	1B		1N	1 Health
	2B		2N	2 Running my own life, making choices
	3B		3N	3 Family relationships
	4B		4N	4 Relationships with friends
	5B		5N	5 Getting out and getting around
	6B		6N	6 What I do all day
	7B		7N	7 Food
	8B		8N	8 Happiness
	9B		9N	9 Comfort
	10B		10N	10 Safety
	11B		11N	11 Treatment by staff/attendants
	12B		12N	12 Health care
	13B		13N	13 Privacy
	14B		14N	14 Overall quality of life

15. How many of these 14 questions were answered by the Focus Person?

_____ (from 0 to 14)

Quality of Life Priorities

(To Be Answered by the Person or Whoever Knows the Person Best)

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Ask the person to rate HOW IMPORTANT each area of quality of life is to him or her. **If the person can't answer, accept answers from whoever knows the person best.**

	Priority to the Person 1 Less important 2 Somewhat Important 3 Very Important 4 Extremely Important 5 MOST Important	Quality of Life Area
1		1 Health
2		2 Running my own life, making choices
3		3 Family relationships
4		4 Relationships with friends
5		5 Getting out and getting around
6		6 What I do all day
7		7 Food
8		8 Happiness
9		9 Comfort
10		10 Safety
11		11 Treatment by staff/attendants
12		12 Health care
13		13 Privacy
14		14 Overall quality of life

Personal Interview

(To Be Answered Only by the Person)

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INSTRUCTIONS

- These questions can be answered **ONLY** by the person, preferably in private.
- There are four situations in which the interview may be done with others present:
 - 1) An interpreter or other helper is needed by the person to complete this interview
 - 2) The person wants someone else to be there with him/her
 - 3) There is any strong objection from any third parties (providers, relatives, guardians)
 - 4) You, the Visitor, feel uncomfortable for any reason being in private with this person
- Try to interview the person, even if there is doubt about ability to respond; **BUT --**
- Keep it informal. Begin with the usual social niceties that you would expect from any visitor to your home. How are you, telling about yourself, comments on the home, etc.
- If the person clearly is not responding or understanding after a little while, you may make a note at the end of this section, thank the person, and terminate the interview.
- Any item with 5-point scale answers should be thought of as a "YES-NO" or "GOOD-BAD" 2-point scale, with a chance to get more detail if the person is able. Example: Ask "How do you feel about living here?" and the person answers "Good" then you probe "Would you say Good or Very Good?" If the person answers "I don't know," or "Not sure," or some indefinite answer, probe with "Do you feel on the good or bad side?" If no preference, stick with "Fair," which we will interpret to mean "In Between."
- Tell the person this interview is **VOLUNTARY**. Say that he/she does **NOT HAVE TO** talk to you. Even if he/she agrees to the interview, he/she can stop at any time, for any reason.

1. Do you want to talk to me about your home, your life, and your feelings?

0 No (STOP)

_____ 1 Yes

2. How do you feel about living here?

1 Very Poor

2 Poor

_____ 3 Fair (In Between, Not Sure)

4 Good

5 Very Good

9 No Answer or Not Applicable - person has no home at present

2A. What do you like about living here?

(Probe: like the best, like the most.)

2B. What do you not like about living here?

(Probe: like the least, dislike.)

3. Who picked this place for you to live in? (REPHRASE AS NECESSARY, USING THE WORDS "CHOOSE," "CHOICES," ETC.)

- 1 Others made the choice (family, professionals, court, etc.)
- 2 Person had little input
- _____ 3 Person had some input
- 4 Person had a major say; decision was shared
- 5 Person chose (even if assisted, person made the final choice)
- 9 Don't Know or Not Applicable

4. How is the food here? (Rephrase if person cooks for him/herself.)

- 1 Very Poor
- 2 Poor
- _____ 3 Fair (In Between, Not Sure)
- 4 Good
- 5 Very Good
- 9 No Answer or Not Applicable (e.g., nutrition via tube)

5. Do you get to pick what's made for breakfast, lunch, and dinner?

- 1 Others make the choice (family, professionals, court, etc.)
- 2 Person has little input
- _____ 3 Person has some input
- 4 Person has a major say; decisions are shared
- 5 Person chooses (even if assisted, person makes final choices)
- 9 Don't Know or Not Applicable

6. Do you have a person-centered plan?

- 0 No
- _____ 1 Yes
- 9 Not sure

7. How do you feel about what's in your person-centered plan?

- 1 Very Poor
- 2 Poor
- _____ 3 Fair (In Between, Not Sure)
- 4 Good
- 5 Very Good
- 9 No Answer, Don't Know, or Not Applicable

8. How do you feel about the people you live with?

(NOTE: THIS QUESTION IS ABOUT ROOMMATES, NOT ABOUT STAFF, WIVES, CHILDREN, PARENTS, ETC.)

- 1 Very Poor
- 2 Poor
- _____ 3 Fair (In Between, Not Sure)
- 4 Good
- 5 Very Good
- 9 No Answer or Not Applicable

9. Did you pick who you live with?

- 1 Others made the choice (family, professionals, court, etc.)
- 2 Person had little input
- _____ 3 Person had some input
- 4 Person had a major say; decision was shared
- 5 Person chose (even if assisted, person made the final choice)
- 9 Don't Know or Not Applicable

10. Do you have enough privacy or not?

1 Definitely Not

2 Probably Not

_____ 3 Maybe (In Between, Not Sure)

4 Yes, Probably

5 Yes, Definitely

9 No Answer or Not Applicable (e.g., lives alone)

11. Would you rather live somewhere else?

1 Definitely Not

2 Probably Not

_____ 3 Maybe (In Between, Not Sure)

4 Yes, Probably

5 Yes, Definitely

9 No Answer or Not Applicable (e.g., lives alone)

11A. IF YES, WHERE? _____

12. How do you feel about the people who (work with you / assist you) here (the staff)?

1 Very Poor

2 Poor

_____ 3 Fair (In Between, Not Sure)

4 Good

5 Very Good

9 No Answer or Not Applicable; no "staff" who work at the home

13. Did you pick the people who (work with you / assist you) here (the staff)?

1 Others made the choice (family, professionals, court, etc.)

2 Person had little input

_____ 3 Person had some input

4 Person had a major say; decision was shared

5 Person chose (even if assisted, person made the final choice)

9 Don't Know or Not Applicable

14. How do you feel about your [job, school, day program, workshop, etc.]?

1 Very Poor

2 Poor

_____ 3 Fair (In Between, Not Sure)

4 Good

5 Very Good

9 No Answer or Not Applicable

15. Did you pick your [job, school, day program, workshop, etc.]?

1 Others made the choice (family, professionals, court, etc.)

2 Person had little input

_____ 3 Person had some input

4 Person had a major say; decision was shared

5 Person chose (even if assisted, person made the final choice)

9 Don't Know or Not Applicable

16. How do you feel about the way things are with you and your family?

1 Very Poor

2 Poor

_____ 3 Fair (In Between, Not Sure)

4 Good

5 Very Good

9 No Answer or Not Applicable

17. Do you have friends or not?

- 1 No Friends
- 2 Just One
- _____ 3 A Few
- 4 Yes, Some
- 5 Yes, A Lot
- 9 Not sure, no answer

18. Who is your best friend?

- 1 Staff Member
- 2 Other Paid Professional
- 3 Advocate, Guardian
- _____ 4 Foster Family Member
- 5 Family Member
- 6 Peer With A Disability
- 7 Unpaid Person Without Disability (Neighbor, Co-Worker, etc.)
- 8 Boyfriend or Girlfriend
- 9 Don't Know or Not Applicable - No Best Friend

19. Do you ever get lonely?

- 1 Yes, Often
- 2 Yes, Sometimes
- _____ 3 In Between, Not Sure
- 4 No or Very Rarely
- 5 No, Never
- 9 No Answer or Not Applicable

20. When you go out places (field trips, shopping, movies, parks, walks, or any other outings), who picks where you go?

- 1 Others make the choice (family, professionals, court, etc.)
- 2 Person has little input
- _____ 3 Person has some input
- 4 Person has a major say; decisions are shared
- 5 Person chooses (even if assisted, person makes final choices)
- 9 Don't Know or Not Applicable

21. Would you like to go out more often, or less often?

- 1 Much less often
- 2 Somewhat less often
- _____ 3 About the same
- 4 Somewhat more often
- 5 Much more often

22. Is religion (faith, church, worship) a large part of your life, or small, or not at all?

- 1 Not at all
- 2 Small
- _____ 3 In between
- 4 Large
- 5 Very large

23. How do you feel about that?

- 1 Very poor
- 2 Poor
- _____ 3 In between
- 4 Good
- 5 Very good

24. Are you involved in self-determination?

1 Definitely Not

2 Probably Not

_____ 3 Maybe (In Between, Not Sure)

4 Yes, Probably

5 Yes, Definitely

9 No Answer or Not Applicable (e.g., lives alone)

25. How do you feel about self-determination, good or bad?

1 Very Bad

2 Bad

_____ 3 Fair (In Between, Not Sure)

4 Good

5 Very Good

9 No Answer or Not Applicable

26. What things are the most important for your happiness? (Up to three things.)

26A _____

26B _____

26C _____

27. What things make you the most unhappy? (Up to three things.)

27A _____

27B _____

27C _____

28. If you had one wish, what would you wish for?

29. Is there anything else you'd like to say?

INFORMATION ABOUT THE HOME

Note: The remainder of this form needs to be collected only once for each home or cottage or living area!
Copy from one booklet to another for each home, cottage, or living area.

Individualized Practices Scale

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INSTRUCTIONS

- 1) Please complete each item by interviewing the respondent (staff person or other caregiver).
- 2) Ask questions in this form: For item #1, "How is waking up handled on weekends and holidays?" Probe the response if necessary, and complete the item according to the answers.
- 3) Omit this scale in an individual home, a foster home, or a family home.

Weekend/Holiday Schedule

1. Waking time
_____ 2 Flexible - people get up at different times
1 Fixed - with exceptions
0 Fixed - same for all
2. Bed time
_____ 2 Flexible - people go to bed at different times
1 Fixed - with exceptions
0 Fixed - same for all
3. Dinner time
_____ 2 Flexible - people can eat at different times
1 Fixed - with exceptions
0 Fixed - same for all
4. TV, Radio, and Music times
_____ 2 Flexible - people watch/listen as individuals
1 Fixed - with exceptions
0 Fixed - times are set for all people by rules

Weekday/Workday Schedule

5. Waking time
_____ 2 Flexible - people get up at different times
1 Fixed - with exceptions
0 Fixed - same for all
6. Bed time
_____ 2 Flexible - people go to bed at different times
1 Fixed - with exceptions
0 Fixed - same for all
7. Dinner time
_____ 2 Flexible - people can eat at different times
1 Fixed - with exceptions
0 Fixed - same for all

8. TV, Radio, and Music times
 _____ 2 Flexible - people watch/listen as individuals
 1 Fixed - with exceptions
 0 Fixed - times are set for all people by rules

General Activities

9. Going to work or day program
 _____ 2 Most people go to different jobs/day programs
 1 Some people go to the same jobs/day programs
 0 All people go to the same jobs/day programs
 9 N/A
10. Recreational trips (malls, parks, sports, walks, etc.)
 _____ 2 Usually as individuals or pairs (1 or 2 people with or without staff)
 1 Sometimes in groups, sometimes as individuals or pairs
 0 Always in groups
 9 N/A
11. Shopping for food
 _____ 2 Usually as individuals or pairs (1 or 2 people with or without staff)
 1 Sometimes in groups, sometimes as individuals or pairs
 0 Always in groups
 9 N/A
12. Doctor, dental, psychiatric, or other health care appointments
 _____ 2 Usually as individuals or pairs (1 or 2 people with or without staff)
 1 Sometimes in groups, sometimes as individuals or pairs
 0 Always in groups
 9 N/A
13. Restaurants
 _____ 2 Usually as individuals or pairs (1 or 2 people with or without staff)
 1 Sometimes in groups, sometimes as individuals or pairs
 0 Always in groups
 9 N/A
14. Worship
 _____ 2 Usually as individuals or pairs (1 or 2 people with or without staff)
 1 Sometimes in groups, sometimes as individuals or pairs
 0 Always in groups
 9 N/A
15. Birthdays
 _____ 2 Celebrated with individual ceremonies, parties, and/or gifts
 1 Sometimes in groups, sometimes as individuals
 0 Always in groups, e.g., all June birthdays in one party
 9 N/A

Home Physical Quality Scale
From Moos, Lemke, & Mehren, 1979, MEAP;
Modified by Temple University, 1983
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INSTRUCTIONS:

- 1) Not to be used in an independent living or family home setting.
- 2) This section is to be completed in private, after a tour of the home.
- 3) Avoid giving the impression of "taking notes" during the tour.
- 4) Some of the judgments may seem subjective, but please try to give ratings according to the concept of an "American average" home.

SECTION 1: EXTERNAL

1. As a neighborhood, how does the area around this home look?
 3 Very pleasant and attractive
 2 Mildly pleasant and attractive
 _____ 1 Ordinary, perhaps even slightly unattractive
 0 Unattractive, slum-like

2. How attractive are the home's grounds?
 3 Very attractive - as nice as, or nicer than, the grounds of the surrounding homes
 2 Somewhat attractive
 _____ 1 Ordinary
 0 Unattractive - the grounds stand out as being "different" and less attractive

3. How attractive is the building?
 3 Very attractive - attractive design, excellent maintenance
 2 Somewhat attractive
 _____ 1 Ordinary
 0 Unattractive - building is deteriorated or unattractive

SECTION 2: ROOM BY ROOM

4. Orderliness/clutter
 3 Neat - living spaces are very orderly
 2 Some disarray
 1 Cluttered
 0 Very cluttered - furniture and other objects are in disarray
 9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM
----------------------------	----------------	----------	---------	----------

5. Cleanliness
 3 Very clean
 2 Clean
 1 Dirty
 0 Very dirty
 9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM
----------------------------	----------------	----------	---------	----------

6. Condition of furniture
 3 Excellent condition - like new, well-kept
 2 Good Condition
 1 Fair Condition
 0 Deteriorated - old and in poor repair
 9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM
----------------------------	----------------	----------	---------	----------

7. Window areas
 3 Many windows
 2 Adequate windows
 1 Few windows
 0 No windows
 9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN
----------------------------	----------------	----------	---------

8. Odors
 3 Fresh - air is fresh and pleasant
 2 Neutral or unexceptional
 1 Slightly objectionable
 0 Distinctly objectionable - unpleasant odors are apparent
 9 No such room at this residence

LIVING ROOM OR DAY ROOM	DINING ROOM	BEDROOMS	KITCHEN	BATHROOM
----------------------------	----------------	----------	---------	----------

SECTION 3: OVERALL

9. Variation in decor of peoples' rooms (apartments.)
 3 Distinct variation - decor varies from room to room
 2 Moderate variation
 _____ 1 Little variation
 _____ 0 Identical - little or no variation
10. Personalization of peoples' rooms (apartments.)
 3 Much personalization - most of the furnishings and objects in the rooms belong to the individual
 2 Some personalization
 _____ 1 Little personalization
 _____ 0 No personalization is evident
11. Overall physical pleasantness of the home
 3 Quite pleasant
 2 Pleasant
 _____ 1 Somewhat unpleasant
 _____ 0 Distinctly unpleasant
12. Neighborhood safety impressions
 3 Very safe neighborhood
 2 Reasonably safe neighborhood
 _____ 1 Somewhat unsafe neighborhood
 _____ 0 Distinctly unsafe neighborhood

Elements Of Normalization

Adapted from Wolfensberger & Glenn, 1975

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Rate these items after the visit is finished, using your general impressions. The items may be somewhat subjective, and that is OK.

1. STAFF ATTITUDES TOWARD PEOPLE LIVING IN THE HOME

- 5 IDEAL: Warmth, affection, and optimism for the future concerning the people living in the home
- 4 GOOD: Positive feelings toward the people
- 3 FAIR: Neutral feelings toward the people, sometimes called "professional attitude," but characterized by overall lack of positive emotional expression
- _____ 2 POOR: Negative feelings toward one or more of the people, such as disdain, contempt, hostility
- 1 UNACCEPTABLE: Negative feelings toward all or most of the people

2. OVERALL INTEGRATION OF HOME

- 5 IDEAL: House or apartment in a regular neighborhood, and is not "next to or very near" other homes or programs for people with special needs, and the neighborhood has a good "image" (in a wealthy suburb, near a respected college, etc.)
- 4 GOOD: Regular neighborhood, and not "next to or very near" to other special homes or programs
- 3 FAIR: Regular neighborhood, but is "next to or very near" to other special homes or programs
- _____ 2 POOR: In a neighborhood that is not "regular;" mixed commercial and residential, or in the midst of many or large special homes or programs
- 1 UNACCEPTABLE: Glaringly segregated situation, such as a large institutional setting, or an area with practically nothing but special homes and programs

3. PERSON-CENTERED ORIENTATION:

- 5 IDEAL: Each individual is thought of, described as, and treated as, a unique person with unique wants and needs, and this is abundantly clear during the entire visit
- 4 GOOD: Same as 5, but less strongly so
- 3 FAIR: Midway between IDEAL and UNACCEPTABLE
- _____ 2 POOR: People are often "lumped together" as a group who are all treated similarly
- 1 UNACCEPTABLE: The people here are clearly not being thought of, described as, or treated as, unique individuals.

Visitor's Subjective Impressions

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1. How happy do you think this person is?

0 1 2 3 4 5 6 7 8 9 10
Very In Between Very
Unhappy Happy

2. What is the quality of staff-consumer interactions?

0 1 2 3 4 5 6 7 8 9 10
Cold, Neutral Warm,
impersonal personal

3. What is the quality of consumer-consumer interactions?

0 1 2 3 4 5 6 7 8 9 10
Unfriendly Tolerant Friendly

4. Staff attitudes about power and control issues (sharing power and choices with person and unpaid allies).

0 1 2 3 4 5 6 7 8 9 10
Grossly In Between Highly
Over- Supportive
Controlling of Choice-
making

5. If you had a close relative with a major disability, how would you feel about him or her living in this home?

0 1 2 3 4 5 6 7 8 9 10
Extremely Neutral Extremely
Negative Positive

6. Was there anything exceptionally NEGATIVE about this home that you feel it is important to describe?

7. Was there anything exceptionally POSITIVE about this home that you feel it is important to describe?

Scale On Advocacy And Rights (SOAR)

(To Be Answered by the Focus Person or the Responding Family Member)

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Ask the focus person to rate the indicators on advocacy and rights. If the focus person can't answer, accept answers from the family member or whoever knows the person best. **Ask for what they believe the focus person would say.**

1. To what extent do you believe your rights are respected here?
_____ 1 Never
_____ 2 Rarely
_____ 3 Sometimes
_____ 4 Usually
_____ 5 Always
_____ 9 Don't know or not applicable

2. Did you experience any dissatisfaction or conflicts with the paid services you received in the past year?
_____ 1 Yes
_____ 2 No

3. If yes, please describe the nature of your conflict
_____ 1 Conflict over service quantity
_____ 2 Conflict over service quality
_____ 3 Other (Please Describe: _____)
_____ 9 Don't Know or Not Applicable

4. Did you receive any assistance in dealing with the conflict?
_____ 1 Yes
_____ 2 No

5. If yes, what kind of support or advocacy services did you access to address the situation?
_____ 1 Relative or family member
_____ 2 Friend or other nonpaid supporter
_____ 3 Self advocacy organization
_____ 4 Other advocacy organization (for example, parent advocacy organization)
_____ 5 Other (please describe: _____)
_____ 9 Don't know or not applicable

6. How satisfied were you with the help you received from your supporter or the advocacy organization?
_____ 1 Very Dissatisfied
_____ 2 Dissatisfied
_____ 3 In Between
_____ 4 Satisfied
_____ 5 Very Satisfied
_____ 9 Don't know or not applicable

7. About how many days did it take for the matter to get resolved?
_____ Days

8. How satisfied were you with the outcome of the situation?
- 1 Very Dissatisfied
 - 2 Dissatisfied
 - _____ 3 In Between
 - 4 Satisfied
 - 5 Very Satisfied
 - 9 Don't know or not applicable
9. Are you involved in any meetings or activities of People First or any other self-advocacy groups?
- 1 Never
 - 2 Once in a while (once or twice a year)
 - _____ 3 Sometimes (3 to 11 times a year)
 - 4 Often (12 to 23 times a year, or about monthly)
 - 5 Very Often (more than 24 times a year, or more than twice a month)

Completion Time

1. _____ Minutes to complete this PLQ, excluding breaks and interruptions.