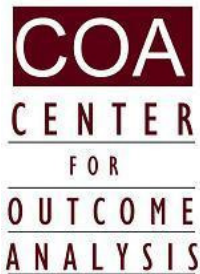


Personal Life Quality Protocol

Short, Reliable Outcome Measurement Tools for Quality Tracking in Developmental Disabilities Systems



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INFORMATION ABOUT THE PERSON

Part 1: Individual Information

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

4. Identification number _____

5. _____
Complete Mailing Address, Including Apartment #

6. _____ 7. _____ 8. _____
City or Town State Zip Code

9. _____
Home Area Code and Telephone Number

10. _____ 11. _____
Primary Respondent's Name Title or Relationship

12. _____
Today's Date

Part 2: Demographics, Legal Status, and Disability

1. PERSON'S DATE OF BIRTH

_____/_____/_____
 Month Day Year

2. PERSON'S AGE

3. SEX

1 Male

_____ 2 Female

4. ETHNIC IDENTIFICATION

Check All That Apply	
	1 White or Caucasian
	2 Black or African-American
	3 American Indian or Alaska Native
	4 Asian
	5 Native Hawaiian or Other Pacific Islander
	6 Hispanic or Latino
	7 Other
	99 Refused, left blank

5. PRIMARY ETHNIC IDENTIFICATION

Check ONE Primary	
	1 White or Caucasian
	2 Black or African-American
	3 American Indian or Alaska Native
	4 Asian
	5 Native Hawaiian or Other Pacific Islander
	6 Hispanic or Latino
	7 Other
	99 Refused, left blank

6. MARITAL STATUS

1 Never married

_____ 2 Married now

3 Married in past, single now

99 Refused, Don't know

7. PARENTAL STATUS

_____ 7a. Number of children

_____ 7b. Number of dependent children

8. LEGAL STATUS

- 1 No guardian or conservator
- 2 Guardian
- _____ 3 Conservator
- 4 Don't Know

9. DISABILITIES AND PERCEIVED SIGNIFICANCE

1 = Major disability 2 = Some disability 3 = No disability

Note: Please allow the person and the person's assistants to define what "some" and "major" mean

	Description	Major Disability 1	"Some" Disability 2	No Disability 3	D/K 99
9A.	Ambulation (Walking)	1	2	3	99
9B.	Autism	1	2	3	99
9C.	Behavior: Aggressive or Destructive	1	2	3	99
9D.	Behavior: Self-Abusive	1	2	3	99
9E.	Brain Injury	1	2	3	99
9F.	Cerebral Palsy	1	2	3	99
9G.	Communication	1	2	3	99
9H.	Dementia (Including Alzheimer's Disease)	1	2	3	99
9I.	Health Problems (Major)	1	2	3	99
9J.	Hearing	1	2	3	99
9K.	Intellectual Disability (Intentionally redundant with Item8)	1	2	3	99
9L.	Mental Illness	1	2	3	99
9M.	Physical Disability Other Than Ambulation	1	2	3	99
9N.	Seizures	1	2	3	99
9O.	Substance Abuse	1	2	3	99
9P.	Swallowing: Inability to swallow independently	1	2	3	99
9Q.	Vision	1	2	3	99
9R.	Other (s) _____	1	2	3	99

Part 3: Housing

1. TYPE OF HOME: What type of home is the person living in now?

Check ONE	
	1A. Living with family or friends
	1B. Board and Lodging
	1C. Housing with Services
	1D. Supervised Living Facilities
	1E. Boarding Care
	1F. Shelter
	1G. Transitional Housing
	1H Nursing Homes, Assisted Living
	1I. Adult Foster Care
	1j. ICF/DD

2. HOW MANY PEOPLE LIVE IN THIS HOME RIGHT NOW?

(“HOME” can usually be interpreted as a unique MAILING ADDRESS - - a group dwelling or individual home or apartment. If this is a congregate care facility, use cottage or living unit or building or wing or other meaningful sub-unit. If there are vacancies, only count how many people live here RIGHT NOW.)

	2A. People in this home (or cottage or living unit etc.)
	2B. People with disabilities (unpaid cohabitants)
	2C. People without disabilities (unpaid cohabitants)
	2D. Paid staff who <u>live</u> here (paid cohabitants)

3. WITH HOW MANY PEOPLE DOES THIS PERSON SHARE A BEDROOM? _____ People

4. HOW MANY DIRECT CARE STAFF WORK AT THIS HOME? (Counting all shifts.)

4A. _____ Full Time Staff (Enter 0 if none)

4B. _____ Part Time Staff (Enter 0 if none)

5. WHAT WAS THE LAST MONTH AND YEAR IN WHICH THIS PERSON LIVED IN A STATE DEVELOPMENTAL CENTER or STATE PSYCHIATRIC INSTITUTION?

5A. _____ / 5B. _____ OR 5C. _____ Check here if never lived in state institution
 Month Year

NOTE: Information about employment/day activity or education setting are collected in next section

COMMUNITY INTEGRATION AND ENGAGEMENT

Part 1: Time, Money, & Integration – During the Day

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Please describe your (the person’s) past week – if last week wasn’t usual, please describe a usual week.

HOURS: Estimate how many hours per week are or were worked, on average, in each kind of work setting

EARNINGS: Estimate how much money per week the person earned or earns from each kind of activity on average

INTEGRATION: Write the number for HOW INTEGRATED the person was:

1	Completely segregated	Never in the presence of people without disabilities
2	Mostly segregated	Some or a little of the time in the presence of people without disabilities
3	In between	In Between
4	Mostly integrated	Often in situation where people without disabilities are, or might be, present
5	Completely integrated	Nearly always in a situation where people without disabilities might be, present

Type of Day Activity	# Hours Work Per Week	\$ Earned Per Week	Integration Level
1. Self-Employed: Has His/Her Own Business			
2. Regular Job (Competitive Employment)			
3. Supported Employment – in Regular Community Job			
4. Supported Employment – Enclave or Job Crew model			
5. Sheltered Employment or Workshop Employment			
6. Pre-Vocational Program or Vocational Rehabilitation Program			
7. Day Habilitation Program (Adult Day Program, Non-Vocational Day Program)			
8. Senior Citizen Program			
9. Partial Hospitalization Program - Mental Health Oriented			
10. Volunteer Work			
11. Public School			
12. Private School			
13. Adult Education - GED, Adult Ed, Trade School, etc.			
14. Community Experience			
15. Other _____			
TOTAL HOURS			xxx

COMMUNITY INTEGRATION AND ENGAGEMENT

Part 2: Integrative Activities Scale – In the Past Four Weeks

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ABOUT HOW MANY TIMES did this person do each of the following in the past four weeks?
(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.")

Next, what is the **AVERAGE** group size in which the person had each kind of experience?

Finally, does this person normally have **ANY** interaction with community members when out?

	How Many Times?	Average Group Size Including Staff?	Does This Person Normally Have Any Interaction with Community Members during this kind of trip or outing? (Neighbors, Shoppers, Travelers, any citizens who are not in the "disability system")				
			None	Little	Some	Much	Very Much
			1	2	3	4	5
1. Visit with close friends, relatives or neighbors			1	2	3	4	5
2. Go to a grocery store			1	2	3	4	5
3. Go to a restaurant			1	2	3	4	5
4. Go to a place of worship			1	2	3	4	5
5. Go to a shopping center, mall or other retail store to shop			1	2	3	4	5
6. Go to bars, taverns, night clubs, etc.			1	2	3	4	5
7. Go to a bank			1	2	3	4	5
8. Go to a movie			1	2	3	4	5
9. Go to a park or playground			1	2	3	4	5
10. Go to a theater or cultural event (including local school & club events)			1	2	3	4	5
11. Go to a post office			1	2	3	4	5
12. Go to a library			1	2	3	4	5
13. Go to a sports event			1	2	3	4	5
14. Go to a health or exercise club, spa, or center			1	2	3	4	5
15. Use public transportation (May be marked "N/A")			1	2	3	4	5
16. Other kinds of "getting out" not listed above			1	2	3	4	5

AUTONOMY OVER DAILY LIFE: Decision Control Inventory

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Ask the person and/or the person's chosen ally to say who actually makes decisions in each area. Use the "Two Either-Or Questions" approach. (e.g., "How do foods for the home get chosen, by paid staff, or by you and your friends/housemates/family?" Then follow up with "OK, would you say Mostly or All that way?") Once the pattern is clear, this scale can be done quickly with just the numbers.

WHO MAKES DECISIONS?

1	2	3	4	5	99
All or Nearly All Decisions Made by Paid Folks	Mostly Made by Paid Folks	Equally Shared Decisions	Mostly Made by Person and/or Freely Chosen Allies	All or Nearly All Made by Person and/or Freely Chosen Allies – relatives, friends, advocates	D/K, N/A

	All Paid 1	Most Paid 2	Equal 3	Most Unpaid 4	All Unpaid 5	D/K
FOOD						
1 What foods to buy for the home when shopping	1	2	3	4	5	99
2 What to have for breakfast	1	2	3	4	5	99
3 What to have for dinner	1	2	3	4	5	99
4 Choosing restaurants when eating out	1	2	3	4	5	99
CLOTHES AND GROOMING						
5 What clothes to buy in store	1	2	3	4	5	99
6 What clothes to wear on weekdays	1	2	3	4	5	99
7 What clothes to wear on weekends	1	2	3	4	5	99
8 Time and frequency of bathing or showering	1	2	3	4	5	99
SLEEP AND WAKING						
9 When to go to bed on weekdays	1	2	3	4	5	99
10 When to go to bed on weekends	1	2	3	4	5	99
11 When to get up on weekends	1	2	3	4	5	99
12 Taking naps in evenings and on weekends	1	2	3	4	5	99
RECREATION						
13 Choice of places to go	1	2	3	4	5	99
14 What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc.	1	2	3	4	5	99
15 Visiting with friends outside the person's residence	1	2	3	4	5	99
16 Choosing to <u>decline</u> to take part in group activities	1	2	3	4	5	99
17 Who goes with you on trips, errands, outings	1	2	3	4	5	99
18 Who you hang out with in and out of the home	1	2	3	4	5	99
SUPPORT AGENCIES AND STAFF						
19 Choice of which service agency works with person	1	2	3	4	5	99
20 Choice of Case Manager (or other term such as SSA, SC, etc.)	1	2	3	4	5	99
21 Choice of agency's support persons/staff (N/A if family)	1	2	3	4	5	99
22 Choice of support personnel: option to hire and fire support personnel	1	2	3	4	5	99
ECONOMIC RESOURCES						
23 What to do with personal funds	1	2	3	4	5	99
24 How to spend residential funds	1	2	3	4	5	99
25 How to spend day activity funds	1	2	3	4	5	99
HOME						
26 Choice of house or apartment	1	2	3	4	5	99
27 Choice of people to live with	1	2	3	4	5	99
28 Choice of furnishings and decorations in the home	1	2	3	4	5	99
WORK OR OTHER DAY ACTIVITIES						
29 Type of work or day program	1	2	3	4	5	99
30 Amount of time spent working or at day program	1	2	3	4	5	99
31 Type of transportation to and from day program or job	1	2	3	4	5	99
OTHER						
32 Express affection, including sexual	1	2	3	4	5	99
33 "Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc.	1	2	3	4	5	99
34 Whether to have pet(s) in the home	1	2	3	4	5	99
35 When, where, and how to worship	1	2	3	4	5	99

____ 36. Check here if you wish to report perception of possibly unfair or excessive domination of this person's life by ANYONE.

PERCEIVED QUALITIES OF LIFE

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

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RESPONDENT:

Ask the person to rate the qualities of his/her own life. **If the person can't answer, accept answers from whoever knows the person best.** You must find someone who the person will allow to answer, or who knows the person on a **day to day basis** better than anyone else.

METHOD:

Each quality item is approached as two “Either-Or” questions. For example, the first Either-Or question on the first item is “Would you say your health is good or bad?” (“In between” is implied, if the person says “neither” or “OK” or “neither” or any similar response. But answers like that have to be checked by probing with “Oh, so it’s in between, not really good or bad?”) Once the person answers, for example, “good,” the follow-up is a second Either-Or question: “Would you say good or very good?”

1	2	3	4	5	99
Very Bad	Bad	In Between	Good	Very Good	Don't know, N/A

Life Quality Area	Very Bad	Bad	In Between	Good	Very Good	Don't know, N/A
1 Health	1	2	3	4	5	99
2 Running my own life, making choices	1	2	3	4	5	99
3 Family relationships	1	2	3	4	5	99
4 Relationships with friends	1	2	3	4	5	99
5 Getting out and getting around	1	2	3	4	5	99
6 What I do all day	1	2	3	4	5	99
7 Food	1	2	3	4	5	99
8 Happiness	1	2	3	4	5	99
9 Comfort	1	2	3	4	5	99
10 Safety	1	2	3	4	5	99
11 Treatment by staff/attendants	1	2	3	4	5	99
12 Health care	1	2	3	4	5	99
13 Privacy	1	2	3	4	5	99
14 Overall quality of life	1	2	3	4	5	99

15. How many of these 14 questions were answered by the Focus Person, even if assistance or interpretation was involved?

_____ (from 0 to 14)

Elements of the Person-Centered Planning Process

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Ask the person to rate each element on a Not True to True five point scale. Phrase each question as “True or Not True” followed by the second probe, such as, “OK, True, but would you say Mostly True or Completely True?”

1	2	3	4	5	99
Not True	Somewhat True	Half True	Mostly True	True	Don't Know, N/A

Plain wording	<i>More detail and jargon</i>	Not True	Some True	Half True	Mostly True	True	D/K
1. VISION Planning really included my hopes, vision, goals, and dreams, what I want my life to look like – this year.	<i>Strong efforts are made to understand the focus person's long term goals, hopes, vision, and dreams, as opposed to short term goals set by others.</i>	1	2	3	4	5	99
2. CONTINUITY My goals, hopes, visions, dreams are looked, reviewed, talked about, and reconsidered every time, every year.	<i>Individual life plans, goals, are not just copied every year, but revisited and reviewed for progress</i>	1	2	3	4	5	99
3. COMFORT Planning meetings are comfortable and relaxed for me.	<i>The meetings are comfortable and relaxed for the focus person. (As opposed to formal and “official.”)</i>	1	2	3	4	5	99
4. CREATIVITY We are creative in planning – solving problems, we “try another way.”	<i>The planning process encourages creativity, new ideas, different ways of thinking.</i>	1	2	3	4	5	99
5. HANDLING DISAGREEMENTS Our planning can handle disagreements.	<i>The planning process allows for conflicts and disagreements, and is able to resolve them.</i>	1	2	3	4	5	99
6. SHARING POWER Cooperation is important in our planning, we all share in making decisions.	<i>The planning process emphasizes cooperation among all participants, as opposed to just professional authority.</i>	1	2	3	4	5	99
7. RELATIONSHIPS Our planning works a lot on my relationships – like family, friends, colleagues, romance.	<i>The planning process emphasizes relationships, in addition to other concerns such as skill development, behaviors, & services.</i>	1	2	3	4	5	99
8. KNOWLEDGE OF MONEY Our planning group knows how much money we have to work with.	<i>The planning group knows the costs of support – staff hours, therapy costs, housing costs, food costs, approved Waiver or Plan budgets.</i>	1	2	3	4	5	99
9. CONTROL OF MONEY Our planning group has <u>control</u> over the money that's used to support me.	<i>The planning group has control over the resources (money) devoted to supports?</i>	1	2	3	4	5	99
10. UNPAID MEMBERS My planning group has unpaid members.	<i>The planning group has unpaid members, not just direct support workers, case manager, and other paid folks.</i>	1	2	3	4	5	99
11. PERSON-CENTERED My planning process is person-centered.	<i>Do you consider this plan to be “person-centered”?</i>	1	2	3	4	5	99

Closest Relationships Inventory

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

- A "close relationship" or friend is anyone the person (or whoever knows the person best) defines that way.
- If there are fewer than 5 close relationships, just describe however many there are.
- If there are close relationships with more than 5 people, please try to count only the closest 5.
- This scale may be left empty, if the person has no close friends; please indicate this with a large "X."
- "Contact" can include phone, letter, computer, or even just waving or saying hello.

	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. Male 2. Female	Romance, Intimacy Is this relationship romantic? 0. No 1. Maybe 2. Yes 99. D/K	Planning Involvement Is this friend involved in planning meetings, Person Centered Planning? 0. No 1. Yes, minor 2. Yes, moderate 3. Yes, major 99. D/K	Duration About how long has the person known this friend? (Years - use fractions and decimals if needed, as in 2.5 years, or 2 1/2 years) (99 = D/K)	Frequency About how many times has the person had ANY 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.) (99 = D/K)
1	1 2 3 4 5 6 7 8 9	1 2	0 1 2 99	0 1 2 3 99	Years	Times in Past 28 Days
2	1 2 3 4 5 6 7 8 9	1 2	0 1 2 99	0 1 2 3 99	Years	Times in Past 28 Days
3	1 2 3 4 5 6 7 8 9	1 2	0 1 2 99	0 1 2 3 99	Years	Times in Past 28 Days
4	1 2 3 4 5 6 7 8 9	1 2	0 1 2 99	0 1 2 3 99	Years	Times in Past 28 Days
5	1 2 3 4 5 6 7 8 9	1 2	0 1 2 99	0 1 2 3 99	Years	Times in Past 28 Days