Quality Tracking Toolkit:

Examples for Consideration

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Assembled for the Minnesota Olmstead Sub-Cabinet Working Team on Measurement & Data

Center for Outcome Analysis
www.eoutcome.org
jconroycoa@gmail.com

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Contents

The Integrative Activities Scale

A scale that has been widely used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986[1]). It measured how often people visit with friends, go shopping, go to a place of worship, engage in recreation, and so on, in the presence of non-disabled citizens. The scale tapped only half of the true meaning of integration; if integration is composed of both presence and participation, then the Harris scale reflects only the first part. Presence in the community is a necessary but not sufficient condition for participation in the community. The scale simply counts the number of "outings" to places where non-disabled citizens might be present. The scale is restricted to the preceding month.

Because the scale was developed by Harris, and was used nationally with both disabled and non-disabled Americans, we have national data for comparison. This scale was also used in the National Consumer Survey of 1990 (Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990[2]) with 13,075 Americans with developmental disabilities. Thus there is a very rich national basis for comparison of individual and group experiences of integrative activities.

The interrater reliability of this scale was reported to be very low when the two interviews were separated by 8 weeks, but very high when the time interval was corrected for (.97). The Integrative Activities Scale is shown on the following page.

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[1] Taylor, H., Kagay, M., & Leichenko, S. (1986). *The ICD Survey of Disabled Americans.* Conducted by Louis Harris and Associates. New York: The International Center for the Disabled, and Washington, DC: National Council for the Handicapped.

[2] Conroy, J., Feinstein, C., Lemanowicz, J., Devlin, S., & Metzler, C. (1990). *The report on the 1990 National Consumer Survey.* Washington DC: National Association of Developmental Disabilities Councils.

Integrative Activities Scale

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ABOUT HOW MANY TIMES did this person do each of the following in ONE 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.")

BEFORE means in the previous living situation, or before the program being evaluated began. I this is part of routine monitoring, use "A YEAR AGO" instead of "BEFORE."
NOW means within the past 4 weeks.

BEFORE (In previous situation – OR – A Year Ago	NOW (Past 4 Weeks)	
1B	1N	Visit with close friends, relatives or neighbors
2B	2N	Visit a grocery store
3B	3N	Go to a restaurant
4B	4N	Go to a place of worship
5B	5N	Go to a shopping center, mall or other retail store to shop
6B	6N	Go to bars, taverns, night clubs, etc.
7B	7N	Go to a bank
8B	8N	Go to a movie
9B	9N	Go to a park or playground
10B	10N	Go to a theater or cultural event (including local school & club
11B	11N	Go to a post office
12B	12N	Go to a library
13B	13N	Go to a sports event
14B	14N	Go to a health or exercise club, spa, or center
15B	15N	Use public transportation (May be marked "N/A")
16B	16N	Other kinds of "getting out" not listed above

17. 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.

18. _____ times out of 10 BEFORE

19. _____ times out of 10 in the past month, NOW

Quality of the Individual Planning Process

The "Elements of the Person-Centered Planning Process" scale taps the degree to which a person's individual planning process follows the general guidelines of person-centered planning.

Most modern support systems now practice some variety of the "person-centered planning" process as described and elaborated by Beth Mount and colleagues John and Connie Lyle O'Brien.[3] As they stated, the emergence of Person-Centered Planning was founded on:

- Seeing people first rather than relating to diagnostic labels;
- Using ordinary language and images rather than professional jargon;
- Actively searching for a person's gifts and capacities in the context of community life;
- Strengthening the voice of the person and those who know the person best in accounting for their history;
- Evaluating their present conditions in terms of valued experiences;
- Defining desirable changes in their lives.

The Elements of the Person-Centered Planning Process scale cannot capture all the intensely personal and subtle elements of what it means to put the person's dreams and hopes at the center of all support planning and delivery – but it does appear to work quite well as a gross index. Moreover, it is in fact sensitive to improvements over time in these "best practices," as seen in dozens of studies of deinstitutionalization and self-determination. (These are cited at www.eoutcome.org,), and many of them can be downloaded; the rest can be requested from COA.)

We compute the scale so that its lowest possible score is 0, and the highest is 100. That way, it is easy to interpret, like a number "grade" or percentile.

[3] Mount, B. (1987). *Personal futures planning: Finding direction for change.* (Doctoral dissertation, University of Georgia). Ann Arbor, MI: UMI Dissertation Information Service. Connie Lyle O'Brien and John O'Brien (2000). *The Origins of Person-Centered Planning: A Community of Practice Perspective.* Atlanta: Responsive Systems Associates.

Elements of the Person-Centered Planning Process, Before and Now

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Ask the person to rate each element "BEFORE" and "NOW." BEFORE means before the person got involved in the new program, initiative, or agency being evaluated. If this is routine monitoring for quality, use "A YEAR AGO" instead of "BEFORE." 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	9
Not true at all	**A little bit true**	**Half true**	**Mostly true**	**Completely true**	Don't know, N/A

How True BEFORE? (Or A Year Ago?)	**How True NOW?**	**Plain wording**	***More detail and jargon***
1B	1N	Planning really includes my dreams.	*Strong efforts are made to understand the focus person's long term dreams. (As opposed to short term goals set by others.)*
2B	2N	Planning tries to build networks of support from family, friends and community.	*The planning process emphasizes building a network of supports from informal, unpaid, or general community sources*
3B	3N	Planning meetings are comfortable and relaxed for me.	*The meetings are comfortable and relaxed for the focus person. (As opposed to formal and "official.")*
4B	4N	Planning meetings happen when we need them, not on some fixed schedule.	*Planning sessions are scheduled flexibly, as needed. (As opposed to a regular set schedule, such as annually.)*
5B	5N	We decide how to do the planning – we don't have to follow a bunch of rules and regulations.	*The planning process is defined by group preferences. (As opposed to defined or regulated by a set of standards, rules, laws, or regulations.)*
6B	6N	We try to be creative in planning – thinking of new ideas, new ways to get things done, different approaches.	*The planning process encourages creativity, new ideas, different ways of thinking.*
7B	7N	Our planning can handle disagreements, we can get past them.	*The planning process allows for conflicts and disagreements, and try to resolve them.*
8B	8N	Our planning is flexible – we will try a different way if something is not working.	*The planning process is flexible, allowing for changes in approach when things do not work.*
9B	9N	If others in the planning group can't agree, I have the final word (as long as it's not dangerous or unhealthy).	*The person has ultimate authority if able and willing to exercise it. (He or she could overrule the entire group on an issue, within safety limits.)*
10B	10N	Cooperation is important in our planning – no one group is 'in charge.'	*Did the planning process emphasize cooperation among all participants? (As opposed to professional authority.)*
11B	11N	Our planning works a lot on my relationships – friends, colleagues – and includes romance if I want it to.	*Does the planning process emphasize the person's relationships? (As opposed to emphasizing skill development, or behavior, or services.)*
12B	12N	Money and figuring out how to spend it is a big part of our planning.	*Does the planning process take money into consideration? (Does the group discuss what supports cost, and what alternatives there are?)*
13B	13N	Our planning group has full control over the money that's used to support me.	*Does the planning group have control over the resources (money) devoted to supporting the focus person?*
14B	14N	Non-professionals (myself and my freely chosen allies) have most of the power over planning decisions.	*Do the unpaid group members have the real power? (As opposed to paid staff and professionals.)*
15B	15N	My planning process is person-centered.	*Do you consider this plan to be "person-centered"?*

Employment & Day Activity Quality & Outcome Measures

We contend that one of the principal factors hindering better transition and employment outcomes for people with disabilities is outmoded policy. With the past 30 years of research and demonstrations of new, more cost-effective models of community integrated employment, has come the understanding that better outcomes are possible.

This understanding began with Mark Gold's "Try Another Way" practices in the mid-1970s, which showed that people with significant disabilities had much more potential than anyone had realized, and that they could all learn useful work skills if we could just figure out how to teach them. Next the rise of Supported Employment models in the 1980s, led by Paul Wehman, Tom Bellamy, Lou Brown, and David Mank, showed that people with significant disabilities could not only learn to do useful jobs, but with support they could do them out in the real world, in community integrated settings.

In the two decades to follow, however, no overall progress was made toward this noble goal in most states. This dismal lack of positive outcomes was documented by Mank as early as 1994.[4]

In the late 90s and early 21st century, much excitement has been generated about self-employment and microenterprises, led by Cary Griffin (Griffin-Hammis LLC) and Doreen Rosimos (IncomeLinks, LLC). Positive outcomes have recently been documented in the professional journals.[5] However, this approach to real income generated is still in its infancy, with very few people yet involved.

The centrality of policy in creating better outcomes is amply demonstrated by wild variations across the states. In a 2000 analysis, members of this team found that community integrated employment outcomes for deinstitutionalized people ranged from 5% in California to 32% in Oklahoma.[6] The only difference they could find between the two situations was the leadership and its focus on employment as a high priority policy. Similarly, Vermont has done away with its Sheltered Workshops, while other states have nearly nothing but workshop and day activity options for people with significant disabilities.

We therefore believe, with considerable scientific backing, that analyzing the policies of the states and nations with the best outcomes will enable us to craft simple, clear policy recommendations that could transform transition and employment for people with significant disabilities.

These outcomes in simple large scale terms will be seen as percent employed in integrated settings. In individual outcome terms, they will show up after a few years of implementation in the hours worked, income, and self-reported attitudes including satisfaction, pride, and fulfillment among citizens with significant disabilities.

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[4] Mank, D. (1994). The Underachievement of Supported Employment: A Call for Reinvestment. *Journal of Disability Policy Studies, 5, 2,* 1-24.

[5] Conroy, J.W., Irvine, R., & Ferris, C.S. (2010). Microenterprise Options for People with Intellectual and Developmental Disabilities: An Outcome Evaluation. *Journal of Policy and Practice in Intellectual Disabilities, Volume 7 Number 4* pp 269–277 December 2010.

[6] Fullerton, A., & Conroy, J. (2000, July). *Integrated Employment for People with Developmental Disabilities Who Moved from Institutions to Community Placements in the Nineties: A Comparison of Two States.* Brief Report Number 19 of the Oklahoma Outcomes Series. Submitted to the Oklahoma Department of Human Services, Developmental Disabilities Services Division. Rosemont, PA: Center for Outcome Analysis.

Outcome Analysis

We conceive of three levels of outcome assessment when integrated employment efforts are implemented: individuals supported, direct employment support workers, and agency.

Outcome 1: Individuals Supported

Each participant will be tracked and their work-related quality of life assessed, including pay, family involvement & support, enjoyment, integration, and productivity. Outcome is higher quality when involved in this initiative than they before.

Measure 1a

"Qualities of Work Life – Then & Now Scale." Measures pride, engagement integration, productivity, transportation, relationships, etc. This scale will show the degree to which people are "better off" when involved in the initiative.

Measure 1b

"Time & Money – Then & Now Scale." Measures time spent, and earnings in, categories of productive activity. This scale will reveal shifts in patterns of time usage and earnings.

Outcome 2: Employment Support Workers

Support Worker Outcomes must include enhanced (or at least maintained) qualities of work life for the people on the "front lines" – without this, employment efforts are doomed to long-term failure.

Measure 2a

"Qualities of Work Life: Direct Support Workers Scale." Measures the essential elements of worker engagement, pride, relationships with management, stress, etc. before and after involvement.

Outcome 3: Agency

Agency culture regarding real jobs for real pay. The methods for assessment will include focus groups and attitudinal websurvey of agency personnel. The object will be to document changes in the way the agency sees its employment mission.

Measure 3a

Up to seven focus groups, using the classic formal method developed by Merton (1956).

Measure 3b

Websurvey to be completed by all agency managers involved in the initiative to capture employment related attitudes and knowledge before and at the end of the first year.

COA's Employment Outcome Evaluation Instruments

We recommend four short and simple components to track the essentials of people's work lives.

1. Individual description

Age, gender, disability, ethnicity, living situation, family involvement, when started, file a tax return, how did you hear about this job?

2. Counts & Amounts: Hours and Dollars

How do people spend their time, and how much money do they earn in setting of various levels of integration?

3. Qualities of Work Life

One page summary of a person's feelings about working (or day activities in general) including satisfaction, relationship, pride, and all the same indicators any citizen would use to evaluate their work life.

4. Support Workers Qualities of Work Life

The worker who supports the person most, on a day to day level, must also have decent working conditions if we are to achieve quality. This must be a part of any evaluation of supported and community integrated employment.

Time, Money, & Integration – Then & Now

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- **THEN means just before starting to train with the Employment Initiative, no matter when that was.**
- **NOW means in the past week – or a recent "typical week" if last week was unusual.**

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 THEN and NOW:

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

Type of Day Activity	# Hours Work Per Week THEN	# Hours Work Per Week NOW	$ Earned Per Week THEN	$ Earned Per Week NOW	Integ. THEN	Integ. NOW
Self-Employed: Has His/Her Own Business						
Regular Job (Competitive Employment)						
Supported Employment						
Sheltered Employment or Workshop Employment						
Pre-Vocational Program or Vocational Rehabilitation Program						
Day Habilitation Program (Adult Day Program, Non-Vocational Day Program)						
Senior Citizen Program						
Partial Hospitalization Program - Mental Health Oriented						
Volunteer Work						
Public School						
Private School						
Adult Education - GED, Adult Ed, Trade School, etc.						
Community Experience						
Other _____						
TOTAL HOURS			xxx	xxx	xxx	xxx

Qualities of Work Life "Then and Now" Scale
For Employment Initiative Participants

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(This form should be completed via interview with the person seeking or holding employment. If the person needs or wants assistance from a friend, relative, or ally, that is fine.)

Ask the person and/or the person's chosen ally to say what life was like in each area, first before beginning to work on job seeking via the Employment Initiative, and now, during participation. Use the "Two Either-Or Questions" approach. Ask if each work area was "good or bad" Then and Now. Example: "Before you decided to train with the Employment Initiative, how was your stress, good or bad"? If the answer is "so-so," "in between," or something similar, probe and make sure that the best answer is 3, "In Between." If the answer is either Bad or Good, follow up with a second Either-Or question, like, "Would you say Bad or Very Bad?" Please do reword, rephrase any item to make sure the person's comprehension is good.

For Each Statement: Bad, Good, or In Between?

1	2	3	4	5	9
Very Bad	**Bad**	**In Between**	**Good**	**Very Good**	Don't Know, N/A

Then	Now	
		1. Ability to get help in my work when I need it
		2. Being good at my work
		3. Being proud of what I do
		4. Boredom (lots of boredom is bad = low score)
		5. Fear of losing my health care and benefits (checks) *(Lot of fear = low score)*
		6. Getting to and from work
		7. Happiness about work
		8. I like what I do during the day
		9. Loneliness during work (lonely = low score)
		10.Looking forward to work
		11. Making enough money
		12. Making my own choices about work
		13. Relationships with customers/co-workers
		14. Relationships with my family
		15. Relationships with my friends
		16. Wearing what I want to work
		17. Working the amount that I want to

How many of these 17 questions were answered with help from someone close to you?

_____

Qualities of Work Life "Then and Now" Scale
For Employment Initiative Direct Support Workers

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Ask the Direct Support Worker (or Support Coordinator or Case Manager) to say what life was like in each area, first before beginning to work with people in the Employment Initiative, and now, during participation.

For Each Statement: Bad, Good, or In Between?

1	2	3	4	5	9
Very Bad	**Bad**	**In Between**	**Good**	**Very Good**	Don't Know, N/A

Then, Before Initiative	Now, During Initiative	
		Ability to deal with bad system rules & regulations
		Ability to get things done on time
		Ability to help people succeed in earning money
		Liking your job
		Number of your responsibilities
		Pride in your work
		Relationships with the people receiving services
		Relationships with people's families
		Relationships with co-workers
		Relationships with your supervisor(s)
		Resources to do your job
		Stress (high stress means low score)
		Understanding your job
		Your job security

_____ How many people are you working with right now?

_____ How many of them are working in (or toward) better employment options?

_____ _____ About when did you first begin working on this employment initiative?
Month Year

A Reliable Measure of Choice Making: Decision Control Inventory

Choice making is accurately measured via a scale called the Decision Control Inventory. It is about who has power and control over a person's life – who really makes choices.

- For adults, the measure distinguishes between power held by paid workers versus power held by the person and the person's freely chosen allies.
- For children (and sometimes for adults who live with relatives), the measure distinguishes between choices made by the person versus choices made by the parents, relatives, friends, or advocates (on the person's behalf).

The Decision Control Inventory (DCI) is made up of 35 items. Each item is a facet of life in which people might make choices. Each item is rated on a 5 point scale, with 1 meaning the person exerts little or no choice, 3 meaning power is shared about equally with others, and 5 meaning the person completely or almost completely makes his/her own choices.

The scale displays excellent reliability, including the three traditional forms: test-retest, interrater, and internal consistency (Conroy, 1995). The most important of these is interrater, and its reliability coefficient was .86, which is very high – the highest possible being 1.00. The scale has also been applied with children in foster care, adults with mental health issues, and elders receiving in-home and facility based supports. We compute the scale so that its lowest possible score is 0, and the highest is 100. That way, it is easy to interpret, like a number "grade" or percentile.

This is the same scale that was used in the Robert Wood Johnson Foundation's Independent Evaluation of its Self-Determination in 19 grantee states (and 6 non-grantee states), as well as in more than a dozen other studies of deinstitutionalization, quality of life, and community integrated employment. It has been shown to be highly sensitive to changes in choice making opportunities, both across support models and over time. This means we can track genuine changes in people's power and control over their own lives – a centrally important outcome as expressed by people themselves in tens of thousands of interviews we have conducted over the past 20 years.

How to Ask the Questions

If the person can respond to questions like these accurately, then the person should, of course, be the source of all information. Some people need help with questions like these, and that is fine, too, as long as the helper knows the person really well. Some people don't use language at all, and whoever knows the person best has to answer all the questions. This is not something we like, or want, to do, but there is simply no other choice sometimes.

Ask each question in the form of two Either-Or questions. Here is an example.

1. "How are choices made about what food to buy for the house when shopping, do the [paid staff, people who work here] pick the foods or do you? (With help from unpaid friends or family if you want or need it.)

Suppose the person says, "staff." Then the follow-up question will be:

2. "Do staff decide completely, or mostly?"

If the person settles on "mostly," the answer should be recorded as a "2."

Many people say right away, to the first question, that the choices are "shared" or staff and the person are "equal" in controlling choices. This is recorded as a "3."

Decision Control Inventory, Before and Now

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Ask the person and/or the person's chosen ally to say who actually makes decisions in each area as shown, from 1 to 5. Use the "Two Either-Or Questions" approach. If decisions are made entirely by PAID PERSONNEL (program staff, Case Manager, agency officials, doctors, etc.), enter "1" for that area. If decisions are made entirely by the PERSON AND/OR TRUSTED FRIENDS, RELATIVES, ADVOCATES, etc., enter "5." If decisions are equally shared, enter "3." "BEFORE" means two years ago. If there is absolutely no information available about the person's life two years ago, these "BEFORE" items must be left blank.

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**

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

Quality of Life Measure – A Scale of Perceptions

The simple 14 item scale of quality of life captures the perceptions of the person (and/or whoever knows the person best on a day to day basis) about qualities of life. It can be set up to collect perceptions about life NOW, plus perceptions about life THEN, at some previous time. This can be useful for people who have moved into a new home but no one collected "pre-move" or "baseline" data. This approach is not as accurate as genuine "before and after" measurements, but is quite useful as perceptions of quality, and has been shown to mirror the "before and after" data fairly well.

There is also an option to collect ratings of how <u>important</u> each dimension of quality of life is to each person. This can reveal the fundamental truth that people differ greatly on what is important to them – which is why quality of life is difficult to "get a handle on" – because it is actually different for everyone. With the importance ratings, it is possible to "weight" each person's quality of life perceptions by how important each dimension is to that specific individual.

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 "THEN" and "NOW." For people living at this setting, this means trying to remember what life was like THEN, before they moved here, versus right now. **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.

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	9
Very Bad	**Bad**	**In Between**	**Good**	**Very Good**	Don't know, N/A

THEN	NOW	
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.** Use the dual "either-or" interview method – the first question is phrased as "Is this among the most important, or the less important?" followed by, for example, "Would you say extremely important or MOST important?"

	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

Measuring Individual Plan Goal Attainment

People have widely varying Individual Goals. They emerge from the very nature of person-centered, purposefully free and idiosyncratic "contracts" that service systems develop with people receiving supports. This is a very positive trend, according to best practice thinking. But many observers believe it makes accurate tracking of progress impossible. We contend that it does not, and there is a 40 year body of literature on the topic that supports this contention.

Goal Attainment Scaling is a general method for assessing achievement of goals and objectives of any kind of project. It has been used across a wide variety of settings, including therapeutic, bureaucratic, and service organizations.[7] Goal Attainment Scaling has been used in thousands of settings over the past 30 years, and is the subject of a lively literature which describes its uses and debates its advantages and shortcomings. In all, however, no demonstrably superior method of quantifying complex social interventions has emerged since Kiresuk & Sherman's original seminal article.

In Goal Attainment Scaling, it is helpful set the person's individual goals into priority sequence. What is the most important goal? What is second? Thus each goal is assigned an importance rating, ranging from 1 to 10. Then each goal is written or rewritten in objectively observable terms. Goal attainment ratings are traditionally arrayed along a range from -2 to +2 as follows:

-2 = Achieved much less than projected
-1 = Achieved somewhat less than projected
0 = Achieved exactly what was projected
+1 = Achieved somewhat more than projected
+2 = Achieved much more than projected

These simple rankings and ratings can be combined mathematically into an overall Goal Attainment rating for each person. These ratings have favorable psychometric properties, and have been widely tested for reliability and validity.

The ratings can be aggregated to the home or day program or provider level, or a region, or a state. They offer a quantitative view of the degree to which the individual goals that are being set via person-centered planning processes are actually being met. This, in turn, provides a way to detect people, sites, and agencies that are either "in trouble" or "exemplary."

[7] Kiresuk, T., & Sherman, M. (1968). Goal Attainment Scaling: A general method for evaluating comprehensive community mental health programs. *Community Mental Health Journal, 4*, 443-453.

Individual Plan Goals Summary & Attainment

The summary below 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. Use the program goal codes on the following page. Rank order the goals in their importance, tell how much each is being addressed by paid and unpaid supports, and the amount of progress made thus far 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.
- 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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Short Description of Top 5 Goals in Plan **Use as few words as possible, please.** 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.	**Goal Code**	**Rank Order of the Importance of This Item** **1=First** **2=Second** **3=Third** **4=Fourth** **5=Fifth** **etc.** **99=D/K**	**Has There Been Any Progress Toward This Item in the Past Year?** **-2=Major Loss** **-1=Some Loss** **0=No change** **+1=Some Gain** **+2=Major Gain** **99=D/K**
1			
2			
3			
4			
5			

CODES FOR PROGRAM GOALS

GOALS CONCERNING INDEPENDENT LIVING AND SELF-CARE SKILLS:

01 Dressing skills
02 Toileting
03 Domestic activities (house cleaning, bedmaking, laundry)
04 Eating (self feeding, use of utensils, table manners, table setting, eating in restaurants, food preparation)
05 Bathing and/or washing
06 Grooming and other hygiene (toothbrushing, hair care, shaving, cosmetics, etc.)
07 Understanding and use of numbers
08 Use of money and purchasing
09 Telling time
10 Handling emergencies (fire precaution, first aid, telephone assistance)
11 Obtaining generic community services (how to obtain medical, religious, psychological, etc., services)
12 Mobility/Travel (getting around home, neighborhood, public transportation, etc.)
13 Personal health care (recognizing signs of illness, use of medications, nutrition, following Doctor's orders, attending to menstruation)
14 Use of telephone
19 Other self-care

GOALS CONCERNING DEVELOPMENT OF SENSORY, MOTOR, AND COMMUNICATION SKILLS

20 Vision: using glasses, correction of eye problems, etc.
21 Hearing: using hearing aid, correction of other ear problems, etc.
22 Ambulation improvement: using physical aids if necessary
23 Arm use and hand-eye coordination: ability to grasp, manipulate, use fine motor skills, use adaptive devices
24 Use of verbal language
25 Use of non-verbal communication: signing, gestures, making needs known, expression of feelings, etc.
26 Use of written language: reading, writing, signs, etc.
29 Other sensory, motor, or communication

GOALS CONCERNING REDUCTION OF CHALLENGING BEHAVIOR

30 Reduction of physical violence
31 Reduction of hostility or threatening
32 Reduction of property damage
33 Reduction of behaviors that disrupt others' activities
34 Reduction of rebelliousness, resistance to rules, instructions, etc.
35 Reduction of running away
36 Reduction of theft, stealing, shoplifting
37 Reduction of lying, cheating, borrowing without asking
38 Reduction of physical violence to self
39 Reduction of stereotyped behavior, odd or repetitive mannerisms, eccentric habits or bizarre oral habits
40 Reduction of inappropriate verbalization or vocalization: loud, repetitive, profane, disruptive, annoying
41 Reduction of inappropriate interpersonal manners: rudeness, over-familiarity, annoying, etc.
42 Reduction of clothing problems: refuses to wear or removes inappropriately, tears or damages, etc.
43 Reduction of withdrawal: extreme inactivity, lethargy, shyness, etc.
44 Reduction of hyperactivity
45 Reduction of any kind of inappropriate sexual behaviors
49 Other behavioral goals regarding reduction of challenging behavior

GOALS CONCERNING DEVELOPMENT OF SOCIAL SKILLS

50 Awareness of others
51 One-to-one interaction: conversation, appropriate behavior, etc.
52 Group interaction
53 Family interaction: with parents, siblings, other relatives
54 Manners, customs, politeness, etiquette
55 Civic and legal duties: laws, respect for rights of others
56 Sexual interaction
59 Other social skill goals

GOALS CONCERNING WORKING

60 Learn the concept of working for pay
61 Increase motivation to work
62 Learn specific job skills
63 Achieve a new or better work placement
64 Learn job-seeking skills: learning where to look, applying, promptness, appropriate dress, interviewing, etc.
69 Other work goals

GOALS CONCERNING EDUCATION

70 Improve motivation to participate and learn in school
71 Learn appropriate classroom behavior (be still, be quiet, pay attention, do assigned activities)
72 Be transferred to a more appropriate or more advanced or more normalizing school placement
73 Achieve mastery of specific academic skills-reading, writing, arithmetic
79 Other education goals

GOALS CONCERNING USE OF LEISURE TIME

80 Learn to use television appropriately: selectively, proper times, etc.
81 Develop hobby(s) - arts, crafts, music, reading, games, collecting, etc.
82 Develop skills in sports/athletic activities: regular exercise, tennis, bowling, swimming, etc.
83 Learn to use community resources more independently: parks, pools, movies, theaters, museums, churches, etc.
84 Learn to plan excursions: day trips, vacations, etc.
89 Other leisure time goals

Reliability Studies

Devlin, S. (1989). *Reliability assessment of the instruments used to monitor the Pennhurst class members.* Philadelphia: Temple University Developmental Disabilities Center.

The goal of this evaluation was to determine the internal consistency, test-retest and inter-rater reliability of the five instruments (BDS Adaptive, BDS Maladaptive, NORM, PQ, GHMS and LS scales) used by Temple University's Developmental Disabilities Center to monitor the progress of the Pennhurst Plaintiff Class members. Twenty-nine class members, who were living in community living arrangements were randomly selected to serve as the subjects for this study. The data suggests that the majority of these instruments provide a reliable means of monitoring the progress individuals with developmental disabilities. Recommendations are made for improving the reliability of the scales through more structured training of the data collectors.

The purpose of the present study was to assess the test-retest reliability, inter-rater reliability and internal consistency of the instruments used by Temple University's Developmental Disabilities Center for the past 11 years. In 1978 Judge Raymond J. Broderick, who was appointed Special Master in the Pennhurst case ordered that data be gathered on the status of every individual living in Pennhurst, a state institution for adults with developmental disabilities. This information was then used to plan for the development of community residences for the Pennhurst residents, following the District Court decision to close Pennhurst. Since 1978 the instruments have been used as a means for monitoring the status of the former residents of Pennhurst who are now living in a variety of community residential programs throughout Pennsylvania.

Fullerton, A. Douglass, M. & Dodder, R. (1996). *A systematic study examining the reliability of quality assurance measures.* Report of the Oklahoma State University Quality Assurance Project. Stillwater, OK.

In a nested design across settings and types of people, reliability of the COA adaptation of instruments for Oklahoma was investigated. Reliability on all scales was found to be acceptable, although some items in the health section were not stable over time. Reliability varied significantly from one year to the next, but in general, the levels of reliability were high and the authors concluded that the methodology was worthy of continuation.

Fullerton, A. Douglass, M. & Dodder, R. (1999). A reliability study of measures assessing the impact of deinstitutionalization. *Research in Developmental Disabilities, Vol. 20, No. 6,* pp. 387-400.

Published version of the report above.

Dodder, R., Foster, L., & Bolin, B. (1999). Measures to monitor developmental disabilities quality assurance: A study of reliability. *Education and Training in Mental Retardation and Developmental Disabilities, 34, 1,* 66-76.

Report of a conservative exploration of interrater and test-retest reliability of seven major scales developed by Conroy et al. Found acceptable reliabilities overall and recommended continued utilization of the scales in quality assurance activities.

Conroy, J. (1995, January, Revised December). *Reliability of the Personal Life Quality Protocol. Report Number 7 of the 5 Year Coffelt Quality Tracking Project.* Submitted to the California Department of Developmental Services and California Protection & Advocacy, Inc. Ardmore, PA: The Center for Outcome Analysis.

Executive Summary: This study of the reliability properties of the Personal Life Quality Protocol (PLQP) has investigated test-retest, interrater, and internal consistency for many of the most important outcome indicators in the package. The results have shown that basic demographic information and simple quality items are being collected accurately. Furthermore, most of the major indicators and scales display extremely good reliability characteristics. The scales of adaptive behavior, challenging behavior, and choice-making are particularly strong.

The way the study was designed produced very conservative estimates of reliability, because test-retest and interrater aspects of measurement error were combined. However, it was possible to separate out the test-retest from the interrater aspects to some degree, following the advice of Devlin (1989). This approach led to three indicators for each important scale:

- the raw correlation, in which test-retest and interrater sources of error were combined,
- the pure test-retest correlation (where respondents at Time-1 and Time-2 were identical), and
- the pure interrater correlation (calculated by a formula which presumes that any error not due to instability over time must be due to lack of agreement across respondents).