개인적 삶의 질 측정도구

발달장애인 시스템에서의 삶의 질 추적을 위한 성과 측정 도구

COA CENTER FOR OUTCOME ANALYSIS

Center for Outcome Analysis

www.eoutcome.org
610.246.5961 email jconroycoa@gmail.com

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Personal Interview 개인적 인터뷰

Every “data collection” visit begins with the person.

모든 데이터 수집은 사람들을 방문하면서 시작된다.

Every visit must include an attempt to speak directly with the focus person in private. \

방문할 때마다 반드시 당사자와 개인적으로 직접 이야기해야 한다.

There are hundreds of such interview questionnaires extant.

수 백 가지의 그러한 인터뷰 설문지들이 현존한다.

We do not believe that any have proven superior – either in content or psychometrics.

우리는 그것이 내용이든 정신측정이든 우월하다고 증명된 어떠한 것도 믿지 않는다.

Each organizational entity may include its own interview here, or choose one from those available. COA has a questionnaire with a 40 year history, but the questions are all basically the same as the others.

각 조직적인 독립체는 그 자신의 인터뷰 또는 사용 가능한 것 중 하나를 선택할 수 있습니다. 성과연구센터는(COA)는 40 년 역사를 가지고 있습니다. 그러나 그 질문들은 모두 다른 것들과 기본적으로 동일합니다.

The way the questions are asked, however, is very important. 질문을 묻는 방법은 매우 중요합니다.

Yes/No questions should be avoided. . 예/아니오 질문들은 피해야 합니다.

They are extremely unreliable. 그들은 전적으로 믿을 수는 없습니다.

Much more accurate five point responses can be obtained in a very simple and clear interview method, used and documented by COA research over decades.

수십 년 동안 COA 연구에서 사용되고 문서화된 인터뷰방법 사용되어 문서화 된 매우 간단하고 명확한 인터뷰 방법으로 5 점 척도 응답에 대해 훨씬 더 정확한 5 점 척도 응답을 얻을 수 있습니다.

The general instructions used by COA are reproduced below as an example of procedure.

절차의 예로 COA 에서 사용하는 일반적인 지침이 아래에 재현되어 있습니다

INSTRUCTIONS
지침들

- These questions can be answered ONLY by the person, preferably in private.

이 질문들은 오직 연구참여 당사자에 의해서만(바람직하게는 사적으로) 답변될 수 있습니다.

- There are four situations in which the interview may be done with others present:
- 인터뷰를 다른 사람들과 함께 할 수 있는 네 가지 상황이 있습니다

1) An interpreter or other helper is needed by the person to complete this interview
   이 인터뷰를 완성하기 위해 연구참여자가 통역자 또는 도우미가 필요하다고 요청할 때
2) The person wants someone else to be there with him/her
   연구참여자가 누군가 자신과 함께 그곳에 있기 원할 때

3) There is any strong objection from any third parties (providers, relatives, guardians)

제 3 자(제공자, 친척, 보호자)로부터 강한 반대가 있을 때

4) You, the Visitor, feel uncomfortable for any reason being in private with this person

당신, 방문객, 이 어떤 이유에서든 사적으로 연구참여자와 함께 있기를 불편하게 느낄 때

- Try to interview the person, even if there is doubt about ability to respond; BUT –
- 대답 할 능력이 의심스럽더라도 그 사람과 면담을 시도하십시오; 하지만-
- 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.
- 비공식적인 관계를 유지하십시오. 당신의 집에 방문객이 올 경우의 일반적으로 기대되는 사회적 신념에서 시작하십시오. 네 상태와 너 자신, 그리고 집에 대한 의견 등을 들려주세요.
- 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.
- 당사자가 분명히 반응을 보이지 않거나 이해하지 못하면 이 장 끝 부분에 기록한 뒤 감사 인사를 하고 인터뷰를 종료 할 수 있습니다.
- 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."
- 5 점 척도의 답이 있는 항목은 "YES-NO"또는 "GOOD-BAD"2 점 척도로 생각해야 하며, 가능한 경우 더 자세한 정보를 얻을 수 있습니다. 예 : "여기에 사는 것에 대해 어떻게 생각하십니까?" 연구참여자가 "좋아"라고 답한 다음 "선생님은 좋았습니까 아주 좋았습니까?"라고 묻습니다. 연구참여자가 "모르겠다"또는 "확실하지 않음"또는 일부 불명확 한 대답을 하면 "좋거나 나쁜 중 어떤 쪽 느낌인지?"를 조사하십시오. 선호도가 없다면 'Fair'를 고수하십시오. 우리는 이를 '중간'을 의미하는 것으로 해석 할 것입니다.

- 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.
- 연구참여자에게 이 인터뷰가 자발적이란 점을 말해주세요. 연구참여자가 당신과 반드시 이야기하지 않아도 되며, 면접에 동의한 뒤에도 언제든지 이유를 불문하고 그만 둘 수 있다고 말해주세요.

Integration 사회통합

The scale used to assess integration was taken from the Harris poll of Americans with and without disabilities (Taylor, Kagay, & Leichenko, 1986). It measures how often people "go out" – to 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 is restricted to the preceding month for accuracy.

이 사회통합 평가 척도는 Harris poll 이 장애 및 비장애 미국인을 위해 개발한 사회통합척도를 활용하였다(Taylor, Kagay, & Leichenko, 1986). 이 척도는 연구참여자들이 장애인이 아닌 시민들과 같이 친구 방문, 쇼핑하기, 예배장소에 가기, 레크레이션 참여 등을 위해 얼마나 자주 "외출"하는 지를 측정합니다. 이 척도는 정확도를 확보하기 위해 지난달로 측정기간을 제한합니다.

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) 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).

이 척도가 해리스에 의해 개발되었고, 장애 및 비장애 미국인 모두를 대상으로 한 국가적 측정에 사용되었기 때문에, 우리는 비교할 국가 통계를 가지고 있다. 또한 이 척도는 1990 년의 국가 고객 설문조사에서 발달장애미국인 13,075 명을 대상으로도 사용되었다(Conroy, Feinstein, Lemanowicz, Devlin, & Metzler, 1990). 따라서 개인적 그리고 집단의 사회통합활동 경험들과 비교할 수 있는 매우 풍부한 국가적 자료가 확보되어 있다. 이 척도의 신뢰도는 2 회 인터뷰가 8 주 떨어져 실시되었을 때 매우 낮았지만 시간 간격을 보정하면 매우 높았다고 보고되었다(.97).

The Harris scale tapped only half of the true meaning of integration – if integration is composed of both presence and participation, then the Harris scale reflected only presence. Presence in the community is a necessary but not sufficient condition for participation in the community. COA has added the columns at the right, which determine the size of the group in which people "go out," and also the extent to which the person has any level or kind of interaction with community members while out.

해리스 척도는 사회통합의 진정한 의미의 오직 절반만을 반영했다. 만약 사회통합이 존재와 참여로 구성되어 있다면, Harris 척도는 오직 존재만을 반영했다. 지역사회에서의 존재는 필수적이지만 지역사회에서의 참여를 위한 충분한 조건은 아니다. 그래서 COA 는 권리, 어떤 사람들이 "외출"할 때 그룹의 규모를 무엇이 결정하는지, 외출시 지역사회 구성원들과의 상호작용의 수준과 종류의 수준에 관한 항목을 추가하였다.

These additions reflect the understanding that "outings" are not sufficient for true integration and community connection. Going out in large groups tends to hamper community connection, and researchers have paid little attention to this aspect of integrative experience before. And whether people have any interaction with community members is also important, and that is measured very crudely via the columns at the right. (An example of an outing that does not promote community connections is the common practice of staff taking six people to a fast food restaurant in a van and staff placing the food orders. This typifies a large group experience with little or no community contact, relationship, or interaction.)

이러한 추가 사항은 "소풍"이 진정한 통합 및 지역사회 연결에 충분하지 않다는 사실을 반영합니다. 대규모 그룹으로 나가는

것은 커뮤니티 연결을 방해하는 경향이 있으며, 연구자들은 이전에 통합 경험의 이러한 측면에 거의 관심을 기울이지 않았습니다. 사람들이 지역 사회 구성원들과 어떤 상호 작용을 하는지 또한 중요합니다. 그리고 그것은 추가된 항목을 통해 매우 조심스럽게 측정됩니다. (밴에 있는 패스트 푸드 레스토랑에 6 명의 장애가 있는 사람들을 데려 간 직원과 음식 주문을 하는 스태프'의 예가 지역사회와의 관계를 증진시키지 않는 외출의 일반적인 관행이다. 이는 지역 사회 접촉, 관계, 또는 상호작용이 거의 없는 대규모 그룹 경험을 의미한다.)

The Integrative Activities Scale is shown on the following page.

사회통합활동들 스케일(척도)는 다음페이지

탈시설 성과 척도(콘로이박사)

Integration 사회통합

1. Visit with close friends, relatives or neighbors 가까운 친구들, 친척 또는 이웃들의 방문
2. Go to a grocery store 상점 방문하기
3. Go to a restaurant 식당에 가기
4. Go to a place of worship 워크숍 장소에 가기
5. Go to a shopping center, mall or other retail store to shop 쇼핑센터 또는 다른 상점에 쇼핑 가기
6. Go to bars, taverns, night clubs, etc. 술집, 나이트 클럽 등
7. Go to a bank 은행 가기
8. Go to a movie 영화관에 가기
9. Go to a park or playground 공원 또는 놀이공원에 가기
10. Go to a theater or cultural event (including local school & club events) 공연장 또는 문화적 이벤트 참석(지역사회 학교 또는 클럽 행사 포함)
11. Go to a post office 우체국에 가기
12. Go to a library 도서관에 가기
13. Go to a sports event 스포츠 행사에 가기
14. Go to a health or exercise club, spa, or center 체육관 또는 스파 또는 지역센터에 가기
15. Use public transportation (May be marked "N/A") 대중교통 이용
16. Other kinds of "getting out" not listed above 기타 다른 종류의 외출

3

Productivity 생산성

The scale captures hours in each kind of activity, and also how much money was earned

생산활동에 대한 투입시간과 소득 파악

Type of Day Activity **낮활동 유형**	**주당 일한시간**	주당소득	**사회통합레벨**
1. Self-Employed: Has His/Her Own Business 자기-고용 : 그/그녀 자신의 사업 갖기			
2. Regular Job (Competitive Employment) 정규직(			
3. Supported Employment – in Regular Community Job 지원고용-지역사회에서의 일반 직종			
4. Supported Employment – Enclave or Job Crew model 지원고용-			
5. Sheltered Employment or Workshop Employment			
6. Pre-Vocational Program or Vocational Rehabilitation Program 취업전 프로그램 직업 훈련 프로그램 또는 직업재활 프로그램			
7. Day Habilitation Program (Adult Day Program, Non-Vocational Day Program) 주간 거주 프로그램(성인 주간보호, 비 직업적 주간 프로그램)			
8. Senior Citizen Program(노인 시민 프로그램)			
9. Partial Hospitalization Program - Mental Health Oriented (직업 치료 병원 프로그램 – 정신 건강을 지향한)			
10. Volunteer Work 자원 활동			
11. Public School 공립 학교			
12. Private School 사립 학교			
13. Adult Education - GED, Adult Ed, Trade School, etc. 성인 교육 -			
14. Community Experience 공동체 경험			
15. Other ________________________기타_______			
TOTAL HOURS 전체 시간			xx

Choice Making and Autonomy inDailyLife 일상생활에서의 선택과 자율성

1. **WHO MAKES DECISIONS?(누가 결정하는가?)**

2. 1	3.
8. All or Nearly All Decisions Made by Paid Folks 9. 모두 또는 거의 모두 결정	10. Made by Paid Folks 11.

	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 쇼핑할때	1	2	3	4	5	99
2 What to have for breakfast 아침을 위해 무엇을 했는가?	1	2	3	4	5	99
3 What to have for dinner 저녁을 위해 한 것들	1	2	3	4	5	99
4 Choosing restaurants when eating out 외식할 때 레스토랑 고르기	1	2	3	4	5	99
CLOTHES AND GROOMING 의복과 몸치장						
5 What clothes to buy in store 가게에서 어떤 옷을 사는가?	1	2	3	4	5	99
6 What clothes to wear on weekdays 주중에 어떤 옷을 입는가?	1	2	3	4	5	99
7 What clothes to wear on weekends 주말에 어떤 옷을 입는가?	1	2	3	4	5	99
8 Time and frequency of bathing or showering 목욕 또는 샤워의 빈도와 시간	1	2	3	4	5	99
SLEEP AND WAKING 잠자기와 깨기						
9 When to go to bed on weekdays 주중에 언제 취침할 지	1	2	3	4	5	99
10 When to go to bed on weekends 주말에 언제 취침할 지	1	2	3	4	5	99
11 When to get up on weekends 주말에 언제 기상할 지	1	2	3	4	5	99
12 Taking naps in evenings and on weekends 저녁 그리고 주말에 낮잠 자기	1	2	3	4	5	99
RECREATION 여가						
13 Choice of places to go 갈 장소를 결정하기	1	2	3	4	5	99
14 What to do with relaxation time, such as choosing TV, music, hobbies, outings, etc. 여가 시간, 티브이 시청, 취미들, 외출 등 휴식 시간에 무엇을 할지 결정하기	1	2	3	4	5	99
15 Visiting with friends outside the person's residence 자신의 주거지 외부에 사는 친구 방문하기	1	2	3	4	5	99
16 Choosing to <u>decline</u> to take part in group activities 단체 활동 참여하기의 경감에 대한 선택	1	2	3	4	5	99

17 Who goes with you on trips, errands, outings 여행, 볼일 보기, 외출에 누구와 함께 갈지	1	2	3	4	5	99
18 Who you hang out with in and out of the home 집안 또는 밖에서 누구와 놀지	1	2	3	4	5	99
SUPPORT AGENCIES AND STAFF **지원기관과 스테프**						
19 Choice of which service agency works with person 서비스 기관 선택하기	1	2	3	4	5	99
20 Choice of Case Manager (or other term such as SSA, SC, etc.) 사례 관리자 선택하기	1	2	3	4	5	99
21 Choice of agency's support persons/staff (N/A if family) 기관의 지원 담당자 선택하기	1	2	3	4	5	99
22 Choice of support personnel: option to hire and fire support personnel 활동보조인에 대한 선택 : 활동지원 고용과 해고 선택 옵션	1	2	3	4	5	99
ECONOMIC RESOURCES **경제적 자원들**						
23 What to do with personal funds 개인적 펀드에 대해 무엇을 할 지	1	2	3	4	5	99
24 How to spend residential funds 주거 비용을 어떻게 쓸지	1	2	3	4	5	99
25 How to spend day activity funds 일일 활동 펀드를 어떻게 쓸지	1	2	3	4	5	99
HOME 집						
26 Choice of house or apartment 주택 또는 아파트 선택	1	2	3	4	5	99
27 Choice of people to live with 동거인 선택	1	2	3	4	5	99
28 Choice of furnishings and decorations in the home 가구와 집 꾸미기에 대한 선택	1	2	3	4	5	99
WORK OR OTHER DAY ACTIVITIES **일 또는 주간 활동**						
29 Type of work or day program 일 또는 주간보호의 유형	1	2	3	4	5	99
30 Amount of time spent working or at day program 일 또는 주간활동에 보내는 시간의 양	1	2	3	4	5	99
31 Type of transportation to and from day program or job 일 또는 주간활동을 위한 이동 수단 유형	1	2	3	4	5	99
OTHER 기타						
32 Express affection, including sexual 성관계를 포함한 선호에 대한 표현	1	2	3	4	5	99
33 "Minor vices" - use of tobacco, alcohol, caffeine, explicit magazines, etc. 담배, 술, 카페인, 성인잡지 등	1	2	3	4	5	99
34 Whether to have pet(s) in the home 애완동물 기르기 여부	1	2	3	4	5	99
35 When, where, and how to worship 종교활동의 때, 장소, 방법	1	2	3	4	5	99

Quality of Life–As Seen by the Person and the Person’s Closest Allies

삶의 질- 당사자와 당사자이 가까운 지원자에 의해 보여 지는 대로

Life Quality Area 삶의 질 영역	**Very Bad 매우 나쁨**	**Bad 나쁨**	**In Between 보통**	**Good 좋음**	**Very Good 매우 좋음**	Don’t know, N/A 응답불가
1 Health 건강	1	2	3	4	5	99
2 Running my own life, making choices 우리 자신의 삶 운영, 선택	1	2	3	4	5	99
3 Family relationships 가족 관계들	1	2	3	4	5	99
4 Relationships with friends 친구 관계들	1	2	3	4	5	99
5 Getting out and getting around 외출	1	2	3	4	5	99
6 What I do all day 일과	1	2	3	4	5	99
7 Food 음식	1	2	3	4	5	99
8 Happiness 행복	1	2	3	4	5	99
9 Comfort 편안함	1	2	3	4	5	99
10 Safety 안전	1	2	3	4	5	99
11 Treatment by staff/attendants 직원(안내원)에 의한 치료	1	2	3	4	5	99
12 Health care 건강 캐어	1	2	3	4	5	99
13 Privacy 사생활	1	2	3	4	5	99
14 Overall quality of life 전반적인 삶의 질	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? 이 14문항중 당사자에 의해 답변된 문항의 수(지원자 또는 통역자를 포함하여)

________ (from 0 to 14)

Indicators of the Individual Planning

Integrative Activities Scale – In the Past Four Weeks

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 1	**Little 2**	**Some 3**	**Much 4**	**Very Much 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

Productivity

Productivity can be reflected by earnings, by the amount of time engaged in daytime activities that were designed to be productive (adult day activities, vocational training, workshops, supported and competitive employment). The scale captures hours in each kind of activity, and also how much money was earned, if any. In recent years, we have added the column at the right, which indicates whether the person was completely segregated from the general public, as in a sheltered workshop, or had some level of contact, no matter how small.

Time, Money, & Integration – During the Day

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**	**Inte-gration 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

Choice Making and Autonomy in Daily Life

The scale of choice making is called the Decision Control Inventory. It is composed of 35 ratings of the extent to which minor and major life decisions are made by paid staff versus the focus person and/or unpaid friends and relatives. Each rating is given on a 5 point scale, where 0 means the choice is made entirely by paid staff/professionals, 5 means the choice is made entirely by the focus person (and/or unpaid trusted others), and 3 means the choice is shared equally. This is the same scale used by the Robert Wood Johnson Foundation in its National Evaluation of Self-Determination in 29 states. The interrater reliability of the Inventory was reported as .86 (Conroy, 1995). The most current version of the Decision Control Inventory is shown on the following page.

Decision Control Inventory

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 decline 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

Quality of Life – As Seen by the Person and the Person's Closest Allies

The "Quality of Life Changes" Scale asks each person to rate his/her quality of life in 14 dimensions of quality. On this scale, we permit surrogates to respond. Surrogates (usually staff persons) were "whoever knew the class member best on a day to day basis." When used in residential settings, approximately 60% of the responses are provided by surrogates. The interrater reliability of the Quality of Life Changes Scale was found to be .76.

Over many years, we have been able to compare responses on this scale over time (e.g., "Now" in 1996 compared to "Now" in 2000). We also compare each year's <u>perceived</u> changes in quality (i.e., "Then" as remembered, versus "Now"). The two approaches have been found to produce highly consistent results. This means that, in any one year, we can obtain reasonably accurate estimates of the degree to which peoples' lives have improved in the 14 dimensions of the scale.

Perceived Qualities of Life Scale

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

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)

Indicators of the Individual Planning Process

Person-Centered Planning, which puts the person being supported at the top of the service planning hierarchy, is more than 30 years old, and is now recognized as “best practice.” It is firmly embodied in the 2014 HCBS Final Rule on Waiver requirements. Yet few scientists have attempted to measure its presence, adequacy, or degree of implementation. COA’s work on this aspect of quality tracking is now 20 years old, and includes tests of validity and reliability.

The “Elements of the Planning Process” scale is designed to reflect the degree to which planning is carried out in a “person-centered” manner. There is also an optional Individual Goals section, which captures a snapshot of the content of the plan’s content. This snapshot includes the nature of the top five goals in the plan, and the amount of effort exerted and progress observed on each individual goal.

This scale was developed in consultation with the founders of the self-determination movement in New Hampshire. It was also reviewed by leaders in the individual planning movement. It does not capture all the aspects of person-centered planning, but it has been found to be sensitive to certain programmatic changes such as involvement in self-determination. It was one of the most important elements of the National Impact Assessment of the Self-Determination Initiative of the Robert Wood Johnson Foundation. It is presented on the following page.

Elements of the Person-Centered Planning Process

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

Individual Goals – Effort & Outcomes

The summary below is intended to get at what is in the person's written individual plan, often called a Person Centered Plan – and to find out if the goals are really being worked on – and whether there's been any progress.

Write each need, desire, preference, goal, or objective very briefly, then proceed to describe each one across the columns.

General instructions:

- Rank ordering the importance of the goals can come from the person, the plan, from your own knowledge of the person, from the opinion of whoever knows the person best. 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.

	PLANNED VERSUS ACTUAL EFFORT ON EACH GOAL: How Much Time and Work on this Goal has There Been Compared to What is in the Individual Plan?							**OUTCOME SO FAR: Has There Been Any Gain or Loss on this Goal in the Past Year**					
	Much Less -2	**A Little Less -1**	**About What Was Planned 0**	**A Little More +1**	**Much More +2**	**D/K 99**		**Major Loss -2**	**Some Loss -1**	**No Change 0**	**Some Gain +1**	**Major Gain +2**	**D/K 99**
Most Important	-2	-1	0	+1	+2	99		-2	-1	0	+1	+2	99
Second	-2	-1	0	+1	+2	99		-2	-1	0	+1	+2	99
Third	-2	-1	0	+1	+2	99		-2	-1	0	+1	+2	99
Fourth	-2	-1	0	+1	+2	99		-2	-1	0	+1	+2	99
Fifth	-2	-1	0	+1	+2	99		-2	-1	0	+1	+2	99

Measuring Relationships – The Ultimate Outcome of "Community"

Measurement of relationships and community connections is notoriously difficult in our field, and has received relatively little scientific attention. The world research literature on measurement of relationships and intimacy is completely dominated by scales that focus on verbal interaction. Yet we know that about half of the people in residential settings do not use verbal language at all, and many others have significant limitations.

The scale following aims to collect data about the person's five closest relationships. It captures their nature – including paid or unpaid – and the intensity of the connection. Human relationships can be measured via intensity, duration, and frequency (though no one would claim that measures everything about our immensely complex and important relationships).

With this kind of simple scale, we can find out whether a person can even name five close relationships – and many cannot. We can find out whether they are relatives or not – and whether they are paid or not. We also learn whether relationships include participation in individual planning, and how long they have lasted. (Many people experience important relationships with paid staff that turn out to be short term because of turnover.) We also learn how often people have contact of any kind with their closest allies.

Closest Relationships Inventory

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.

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. Friend- unpaid, non relative**	**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 ½ 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

Contact 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

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

Home

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 live 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