

***A Sampler of Agency Self-Assessment
Activities Related to
Person Centered Planning***

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RECOMMENDED SELF-ASSESSMENT OPTIONS AT A GLANCE

Option	Focus	Time Commitment	Organizing Concept (Example)	Organizational Level of Effort
Structured Meetings	Stakeholder participation & general appraisal	Monthly to twice monthly meetings	Five Accomplishments of Person Centered Approaches	-Low -Can be of limited scope
Self-Review of Organizational Units	Stakeholder participation & a range of services	Monthly to twice monthly meetings	Ten Characteristics of Person Centered Planning	-Low -Can be of limited scope
Comprehensive Self-Review	Stakeholder participation & specific service sites or types of services	Monthly to twice monthly meetings	Valued Outcomes for Californians with Developmental Disabilities	-Moderate -Tends to be broad in scope
External Review	Stakeholder participation & wide range of services or entire organization	Periodic Extensive Commitment of Consumer, Staff and Management Time	CQL Personal Outcomes Measures	-Moderate to High -Tends to be broad in scope
Organization-Wide Management Information System	Stakeholder participation in design & narrow to wide range of services	Periodic staff surveying with specialized surveys combined with consumer surveys	Person Centered Practices, Choice, Participation, Community Involvement	-High -Tends to be broad in scope -May require extensive analysis

Overview of Agency Self-Assessment

This technical assistance report reviews self-assessment approaches related to person centered planning that rely on qualitative and quantitative models for self-monitoring and self-review of operations. Self-monitoring involves any systematic process by which the management of an organization gathers information to ascertain:

- (1) whether person centered services and supports are being provided in the manner intended,
- (2) whether intended changes in organizational processes or activities are implemented, and
- (3) to what degree outcomes that have been established as organizational benchmarks are achieved.

In the developmental disabilities services sector, for more than two decades, organizations providing services and supports to people with disabilities and their families have sought to improve the individualization of services. Twenty years ago, the primary model for achieving individualization of care and services was the interdisciplinary team model; today the primary model relies on person centered planning.

The inception of person centered planning has been accompanied by burgeoning interest in its implementation as well as the extent to which it results in more individualized services and supports and enhances the lifestyles of people with developmental disabilities.

The Task of Implementing Person Centered Supports and Services

Succinctly put, managers of an agency may reasonably believe that they are implementing a variation of person centered planning in a manner that is faithful to person centered principles, but recent research suggests that at times this confidence may be misplaced. The research indicates that providers and families may not always identify personal priorities accurately, and further indicates that managers cannot always assume that changes in how people talk about consumers and services are actually reflected in more person centered ways of providing services and supports. These realities make it necessary to establish a process of actively seeking out information for management and service improvement. Implementation of person centered planning is no simple matter, but entails complexities of organizational development and change, and depends in good part on how business is conducted within the team or group meeting.

Some of the discrepancies that occur between ideal and real implementation of person centered planning reflect the complexities of follow-through with individualized activities and lifestyle changes, as well as:

- (1) constraints on provider agency resources,
- (2) inconsistencies among and within provider agencies regarding how person centeredness is defined,
- (3) failure to implement person centered processes at the plan, team, and organizational levels, and
- (4) uncertainty regarding which aspects of person centered planning constitute inputs or processes and outputs or outcomes.

Provider Agency Self-Monitoring

There is abundant evidence that effective managers in developmental disabilities and mental health agencies engage in fact-finding as a routine part of their management activities. In fact, journals are replete with studies in which agencies gathered performance data in order to identify strengths and vulnerabilities associated with day-to-day operations and development of individualized plans. Although avoidance of penalties associated with being out of compliance with regulations certainly is a factor that encourages self-monitoring or self-review, the need for management to have timely information in order to make informed decisions about program improvement, staff training priorities, and effective use of scarce resources also encourages self-monitoring for many managers.

Agencies, in collaboration with researchers or evaluators, have investigated numerous aspects of program operations through self-monitoring or self-reporting efforts. Such aspects include self-determination, consumer independence, choice-making, and reciprocity in relationships. Agencies have also engaged in self-review and evaluation of key organizational factors that contribute to, or interfere with, enhancement of individualized services and supports. Organizational aspects that have been studied include appropriate staff matching, levels of family satisfaction with person centered planning, methods for enlisting stakeholders, and day-to-day barriers to individualized services and supports. Furthermore, a number of operations studies entailing self-monitoring have addressed the utility of individual service plans (ISPs) with particular attention to such concerns as age-appropriateness, outcomes of planning, and leisure and integration activities.

Considerations of Cost-Benefit and Self-Monitoring

As in other aspects of management that involve assignment of staff and other resources, design of self-monitoring activities involves considerations of cost-benefit. During times of organizational change, especially in transition from program-based to individual-centered services and supports, self-monitoring and collection of management information become more important, and they require heightened attention by managers.

During times of such change it is seldom sufficient to maintain a primary focus on regulatory compliance. Rather, concerns for the performance of personnel--staff, managers, and clinicians--in acquiring needed skills to promote individualization and collaborate in organizational change, as well as concerns about whether new individual and organizational goals are being met, mean that the focus of self-review must be extended beyond analysis of compliance.

An expanded scope of self-assessment, self-monitoring, or self-review implies increased costs in time and resources for these activities, but often resources are scarce to meet these increased costs. As a result, the design of an expanded scope of self-monitoring should be carried out with an eye to identifying:

- (1) key *organizational goals* and objectives that merit special review,
- (2) key *personnel* who are best situated to monitor achievement of those goals and objectives,
- (3) a narrow range of *critical process indicators* to be monitored,
- (4) a narrow range of *critical outcome indicators* to be monitored,
- (5) a plan for systematic *data collection methods* that imposes limited additional burden on individual staff members, but also clarifies tasks for staff and gets the job done,
- (6) a *single person* to be responsible for assuring that monitoring processes are implemented, are maintained, and result in useful management information, and
- (7) a method for *monitoring* and assessing the suitability of these provisions after they have been implemented.

Although each of these aspects of management could be addressed in much more detail, here we focus on some suggested methods for collecting information that may provide management benefits. In the following sections, we present options for self-monitoring of individualization of both service delivery and organizational activity including:

- (1) structured assessment meetings;
- (2) self-review by organizational units;
- (3) self-review following a California example;
- (4) the use of external review or consultation; and
- (5) organization-wide self-assessment using management information systems.

In the following sections of this guide, five approaches to self-assessment are presented in order of increasing complexity, time commitment, and involvement of staff at multiple organizational levels. In some cases, modest commitments of resources to self-assessment can lead to improvements in management and program or service performance. For other agencies more extensive strategies for self-assessment may also be feasible. As with quality improvement activities generally, these methods will complement and contribute to, but not necessarily replace, long-established quality assurance activities routinely implemented by managers.

Structured Meetings: A Focus Group Process for Stakeholders

This option for self-review and organizational renewal involves a group of stakeholders who meet periodically to provide *formative* and *summative* evaluative information to management as a basis for setting objectives for organizational change. Formative information guides development of services and supports, whereas summative information reflects outcomes or impacts of provision of services and supports.

Participants: Recommended participants at each focus group include at least one representative from each of these groups: consumers, families, agency finance managers, agency program managers, direct service personnel, clinicians, and the Board of Directors. Agencies may find it valuable to invite several consumers and several families to participate in this process to assure diverse representation of these groups.

General Methodology:

Method: Sessions should be held at the agency offices on a regular basis, where the status of individualization of services is discussed and targets for organizational improvement are identified. Although sessions can be held with newly constituted groups of people each time, it also may be valuable for at least one focus group to meet repeatedly, and for that group membership to remain stable. To enhance the effectiveness of these efforts to identify targets for improvement, a systematic meeting format, such as Total Quality Management with facilitation, will enhance the group process. Each meeting should result in agreed upon information gathering, and actions to be taken immediately.

Meeting Schedule: Sessions should occur monthly or, preferably, twice monthly. These sessions should provide sufficient interaction among members of the group to encourage group cohesion and collaboration, as well as continued effort, and stimulate timely response and investigation of new opportunities. Sessions should be scheduled well in advance to assure that group members will be able to attend.

Time Commitment: Meetings should be between 1.5 and 2.5 hours to assure that closure or reconciliation can be achieved with respect to present steps to be taken or tasks to be completed before the next meeting, and specific next steps to be addressed during the next session.

Organizing Framework: In order to further focus the content of sessions, the *Five Accomplishments of Person Centered Approaches* (O'Brien & Lyle, 1987) can be used as a sequential framework for meetings (Note: Here and elsewhere in this report specific published materials or products are suggested for use, but others might be used just as effectively.) More specifically, the first several sessions, through general discussion of various elements of the Five Accomplishments, can focus on development of participant skills related to accomplishments, and each subsequent meeting can focus on a single Accomplishment.

Focus on a single Accomplishment should be based on identification and resolution of issues with a small number of people with developmental disabilities, perhaps three or four, who have diverse needs and circumstances, and who are used as "reference" or "index" individuals to frame discussion throughout the process. Using this approach, a full cycle of self-review, encompassing the Five Accomplishments would require up to four to five months to complete, with twice-monthly meetings. The Five Accomplishments are adapted to an organizational focus and paraphrased below, as taken from O'Brien and Lyle (1987).

The Five Accomplishments (O'Brien & Lyle)

Community Presence entails presence in the ordinary places that are typical of community life. In determining whether community presence is occurring, the review group should consider what places the people they serve use regularly or on a repeated basis, and which of these they use alone or alone with assistance.

- *What settings do they use as part of a group of two or three people, or as part of a larger group?*
- *If people are using and participating in typical community places in groups, does this reflect choices by the individuals to participate as a group of peers or friends?*

In determining how the agency might increase presence, several different aspects of agency and individual activity can be considered.

- *In which other types of community settings have people expressed interest in participating, based on discussions on this topic, presence and experience in a wider range of settings, or interest demonstrated by their reactions to participation?*
- *What are the factors that are hindering or affecting participation of people in preferred activities and settings?*
- *What resources or changes in day-to-day operations would be required to increase the individualized community participation levels of most or all of the people served?*
- *Would training or teaching of particular or critical skills to staff or consumers make it possible for some people to participate in community settings much more fully or actively?*

Choice is the experience of autonomy and control in everyday matters such as what to eat or what to wear, and in life-defining matters such as with whom to live or what sort of work to pursue.

In determining the extent to which choice is a common feature of services, a variety of questions can be posed.

- *What decisions are regularly made by the people served by the agency?*
- *What decisions are typically made for these people by others?*
- *Which decisions now made on behalf of consumers by others, could instead be made by the consumers themselves?*
- *For which decisions could each person's role in decision-making be increased?*
- *How does the agency determine limits for each person's decision-making? In other words, how does it respond to concerns regarding autonomy and safeguarding?*

In determining how to increase the range and variety of both lifestyle and consequential decisions made by the people who are served by an organization, it is valuable to consider at least two aspects of agency activity.

- *What changes in procedures, activities, involvement, training, or teaching would be required to increase the number, variety, and importance of the decisions that these people make?*
- *What procedures can and should be employed to increase understanding by others of their interests and preferences?*

Competence involves performance of functional and meaningful activities, when people are provided with the level and type of assistance required in order to assure or allow participation.

Issues related to the enhancement of competence focus on valued outcomes and also on the specific activities undertaken by agencies to address competence as a contributor to attainment of valued outcomes.

- *What skills could people develop that would increase opportunities for them to engage in increased presence, choice, and participation in valued activities?*
- *What strategies for instruction and assistance have been most effective as interventions to increase each person's skills and abilities in the past?*
- *If involvement in skill instruction is a preferred activity, can other strategies such as environmental modification, personal assistance, or activity sampling be used to enhance presence, participation, or choice while these skills are being learned?*
- *If involvement in skills instruction is not a preferred activity for each person, or the likelihood of meaningful benefit of instruction in particular or critical skills is low, can other strategies, such as environmental modification, personal assistance, or activity sampling enhance presence, participation, or choice?*
- *Do people have health-related problems that hinder choice or participation, and how can these be managed so that negative impacts of health care needs on choice and participation are diminished?*

Respect involves being a valued member of a network of friends, acquaintances, relatives, or concerned people and fulfilling valued roles in one's community.

First, review of efforts or changes needed to increase respected participation entails consideration of the roles that people fulfill currently.

- *What are the valued community roles that people fulfill now, and what percentage of time is spent engaged in each of these roles?*
- *Which community roles that are available or could be developed offer people the best opportunity to express individual talents or skills, and reflect personal preferences?*
- *What changes in how the agency is organized or how it conducts its operations would be necessary to increase the amount of time each person spends engaged in valued roles in the larger community?*

Secondly, review of efforts or changes needed to increase respect entails analysis of the extent to which the people whom the agency serves are viewed by the larger community as valued individuals.

- *What opportunities and aspirations have been discussed with people as options for them individually?*
- *Do people engage in behaviors or have limited skills that can be enhanced but that presently reinforce stereotyped perceptions of people with severe handicaps held by members of the larger community?*
- *Are there typical characteristics of the agency, program, or service environment, or publications of the agency that reinforce stereotyped perceptions of people with severe handicaps held by members of the larger community?*
- *What changes in routines, activities, involvement, socializing, skill building, or participation could be implemented to decrease the extent to which people experience stigmatization?*

Community Participation involves membership in a network of personal relationships that includes close friends and other people in the larger community with whom someone interacts on a recurring, repeated, or regular basis.

A first step in the analysis of community participation entails identifying the extent to which people are currently participating in community life.

- *What neighborhood and community resources are available within walking distance of the places where the agency typically serves people?*
- *With whom do people spend the most time on a daily and weekly basis?*
- *How many of the people with whom participants spend their time are people with disabilities served by the agency, or other local providers of services?*
- *How many of the people with whom participants spend time are human services professionals or staff who work for the agency?*
- *Are there other important people in social networks with whom each person spends time at least occasionally?*
- *Do people have friends, acquaintances, or others with whom they have self-selected relationships?*
- *Who knows each person's desires, aspirations, and personal goals well? Can these same people act as advocates for each person's interests?*

A second step in the analysis of community participation entails identifying changes in agency activities, routines, or operations that are necessary to increase the extent to which participation typifies the lives of people who are served.

- *What changes in agency operations and organization of services are needed to reinforce and expand each person's present network of relationships (for example, transportation arrangements, staff deployment and work schedules, safeguarding, spending money)?*
- *What changes in agency operations and organization of services are needed to increase the number of people without disabilities, including peers, who spend time with each person as a companion or friend?*

Agency Self-Review of Organizational Units

This option for self-review and organizational renewal involves a group of stakeholders who meet periodically to report back formative and summative evaluative information (i.e., data and findings) to management as a basis for improving the performance of specific organizational units (e.g., programs or service groups). Formative information guides development of services and supports, whereas summative information reflects outcomes or impacts of provision of services and supports.

Participants: Recommended participants include one or two representatives of each major program area of activity, e.g., residential services, in-home services, day services, family support services, quality services, and management. Participants should include representatives from among consumers, families, agency personnel at various levels, and the Board of Directors.

General Methodology:

Method: Sessions should be held at the agency offices or rotated among program or service locations on a regular basis. Key issues in individualization of services should be discussed in terms of their status and identification of targets for organizational improvement. To enhance the effectiveness of these efforts to identify targets for improvement, a systematic meeting format should be used to guide group process. Each meeting should result in agreed upon information gathering or actions to be taken to begin immediately.

Meeting Schedule: Sessions should occur at least monthly, but preferably twice monthly, to provide sufficient interaction among members of the group, continuance of effort, and stimulate timely response and investigation of opportunities as these are identified. Sessions should be scheduled well in advance to assure that group members will be able to attend.

Time Commitment: Meetings should be between 1.5 and 2.5 hours to assure that new information can be adequately reviewed and conclusions drawn, and that reconciliation can be achieved with respect to steps to be taken or tasks to be completed before the next meeting.

Organizing Framework: In order to further focus the content of sessions, the *Ten Characteristics of Person Centered Planning* (developed by Beth Mount) can be used as a framework for gathering data and structuring review topics at meetings. More specifically, the first several sessions can focus on the selection of "index" individuals, one or more people served by each organizational, program, or service group, who will be the focus of lifestyle and service review and needed organizational adjustments. Subsequent meetings can be structured for in-depth review of a specific organizational group and needed changes based on findings collected in the previous two weeks regarding the index person.

At least one meeting should be dedicated to review of a specific organizational unit, for example, residential services. The entire breadth of information gained from index consumers using the *Ten Characteristics* should be fully considered in each meeting. Because the group will be developing skills in identifying key issues and improvements using the *Ten Characteristics* as a structure, the entire process of review should occur twice, in a cycle. In other words, all organizational units should be reviewed in order of importance, and then reviewed once more. This will ensure that groups reviewed early in the first cycle have the benefit of lessons learned from the process later on. The second review will also permit the group to confirm that gains in individualization have been made, and the nature of those gains

A full cycle of self-review, encompassing the *Ten Characteristics* and review of each organizational unit twice may require up three to four months to complete, with twice monthly meetings. The *Ten Characteristics* have been adapted to an organizational focus as the Personal Futures Planning Indicators (Holburn & Mount, 1996)

and are shown below. The twelve statements that constitute the Indicators can be used with a yes/no response format, or with a rating scale such as a five point scale for "always" to "never," or from "strongly agree" to "strongly disagree." The statements are to be rated based on how the planning that is underway for the person is best described. It is important for every statement to be considered in review.

Personal Futures Planning Indicators

[Twelve Indicators Reflecting Ten Characteristics of Person Centered Planning] **(Holburn & Mount)**

Desire for Change. The focus person, or someone who cares about the person, wants things to change. There is an interest that leads to voluntary commitment to work together.

Positive View of Personal Capacities. The group is able to understand the person in a way that emphasizes his or her capabilities and potential, and the group recognizes and uses their own capacity as individuals.

Personal Vision for A Rich Community Life. A vision and its details relate primarily to the community.

A Circle of Support. A support circle has been formed that consists of people who care and who give their time voluntarily. It is diverse group of people that does not consist entirely of human-service workers.

A Skilled Facilitator. A facilitator guides the group in developing a common vision for the person. The facilitator is a good listener and encourages participation of all group members. After the initial plan is developed, the facilitator comes to follow-along meetings.

A Committed Champion. There is a person on the team who has a personal relationship that transcends legal requirements, rules, and a sense of social justice. A champion is not simply an advocate. A champion is there for the person for the long haul, and does not "leave the scene" when the problem has been solved.

A Community Builder. There is a member of the support circle who is familiar with the local community and brings to the group the community's knowledge and folklore. The community builder is not necessarily expected to make all the connections but can help in determining who needs to talk with whom.

Connections to a Wider Community. Some members of the support circle are actively involved in community organizations, self-help groups, and interest groups. They can provide essential connections to resources often overlooked when we consider only official "systems" responses to individual needs.

An Agency Committed to Change. At least one agency involved in the person's life is committed to doing things differently.

Influence with People in Authority. Some members of the support circle have direct contact with people in authority. They can make face-to-face contact to increase the likelihood of substantive change.

Flexible Resources for Personal Support. Small amounts of time and money are available to do creative things that meet needs identified by the support circle.

A Productive Ongoing Process. The team meets on a regular basis to review the person's status, follow-up on action steps, and work productively to make the vision become a reality.

Self-Review: The California Example

Like the previous examples, this option for self-review involves a group of stakeholders, who meet periodically to report back formative and summative evaluative information (i.e., data and findings) to management. However, this option focuses on the performance, on an enduring basis, of a particular organizational unit (e.g., one program, service, or service location). Formative information guides development of services and supports, whereas summative information reflects outcomes or impacts of provision of services and supports.

Participants: Recommended participants include one or two representatives of each of the stakeholders in a setting, including consumers, families, management, direct service staff, and clinicians, as well as a representative of the Board of Directors. For example, this process might focus on a particular individualized residential arrangement, and include the people who live there, their families, staff, and others who are involved in their lives on a continuing basis.

General Methodology:

Method: Sessions should be held at the program or service location that is the focus of the meetings. Meetings should be held on a regular basis. The status of key issues in individualization of services for specific consumers should be discussed and targets for organizational improvement that reflect problems in how individuals are being served should be identified. To guide group process and enhance the effectiveness of these efforts to identify improvement targets, a systematic meeting format should be used. Each meeting should result in agreed upon information gathering or actions to be taken immediately. The primary actions to be taken should involve resolving difficulties in individualizing services and supports for particular individuals. Secondary actions to be taken should include changes in management practices, and resolution of staff-related concerns. Often, these types of changes will need to be made in order to address individual consumer issues.

Meeting Schedule: Sessions should occur twice monthly, or more frequently. Meetings should provide sufficient interaction among members of the group to encourage continued effort, and stimulate timely response and investigation of opportunities as they are identified. Sessions should be scheduled well in advance to assure that group members will be able to attend.

Time Commitment: Meetings should be between 1 and 1.5 hours to assure that new information can be adequately reviewed and conclusions drawn, and that reconciliation can be achieved with respect to steps to be taken or tasks to be completed before the next meeting. Frequent, but relatively short sessions of this type, when properly structured, will help to maintain a group problem-solving process that addresses specific issues in each meeting.

Organizing Framework: In order to further focus the content of sessions, a series of Valued Outcomes (for example, the *Valued Outcomes for Californians with Developmental Disabilities*) can be used as a framework for gathering data and structuring review of concerns of individual consumers at meetings. The first several sessions can focus on a general discussion of how group members would know whether each valued outcome was occurring for each consumer served by the program. Subsequent meetings can be structured for in-depth review of the circumstances, experiences, routines, and community and social involvement of particular people and specific organizational and individual group changes based on findings collected on the focal people and their activities.

At least one meeting should be dedicated to review of each person served, and the entire breadth of information gained from index consumers using the *Valued Outcomes* should be fully considered in each meeting. Because the group will be developing skills in identifying key issues and improvements using the *Valued Outcomes* as a structure, the entire process of review should be recycled at least once, following separate reviews of each

organizational group. This will ensure that consumers involved and reviewed earlier have the benefit of further assessment that reflects lessons learned from the process, and experience gained from try-outs of changes in practices within units that were reviewed later in the sequence.

A full cycle of self-review, encompassing the *Valued Outcomes* and review of each organizational unit twice may require up three to four months to complete, with twice monthly meetings. Further information regarding the *Valued Outcomes* can be obtained by visiting Allen, Shea, and Associates on the Internet at www.allenshea.com/outcomes.html or www.allenshea.com/qolreview.html, or by reviewing provider and visitor handbooks published by the California Department of Developmental Services (1998a, 1998b).

Valued Outcomes for Californians with Developmental Disabilities
(Allen, Shea, and Associates)

Adopted by the California Department of Developmental Services, May 1995

CHOICE

1. Individuals identify their needs, wants, likes and dislikes.
2. Individuals make major life decisions.
3. Individuals make decisions regarding everyday matters.
4. Individuals have a major role in choosing the providers of their services and supports.
5. Individuals' supports and services change as wants, needs, and preferences change.

RELATIONSHIPS

6. Individuals have friends and caring relationships.
7. Individuals build community supports which may include family, friends, service providers/professionals, and other community members.

LIFESTYLE

8. Individuals are part of the mainstream of community life and live, work and play in integrated environments.
9. Individuals' lifestyles reflect their cultural preferences.
10. Individuals are independent and productive.
11. Individuals have stable living arrangements.
12. Individuals are comfortable where they live.
13. Children live in homes with families.

HEALTH AND WELL-BEING

14. Individuals are safe.
15. Individuals have the best possible health.
16. Individuals know what to do in the event of threats to health, safety and well-being.
17. Individuals have access to needed health care.

RIGHTS

18. Individuals exercise rights and responsibilities.
19. Individuals are free from abuse, neglect and exploitation.
20. Individuals are treated with dignity and respect.
21. Individuals receive appropriate generic services and supports.
22. Individuals have advocates and/or access to advocacy services.

SATISFACTION

23. Individuals achieve personal goals.
24. Individuals are satisfied with services and supports.
25. Individuals are satisfied with their lives.

External Review or Consultation

Unlike the other approaches presented in this sampler, this option entails obtaining external assistance, via contractors, for review of agency performance and stakeholder perspectives. However, like other approaches, this option focuses on performance on a daily basis, and although it can focus on particular organizational units (e.g., specific programs, services, or service locations), it is far more likely to be used to review the gamut of agency operations.

Participants: Recommended participants include representatives of each of the stakeholder groups involved in the everyday activities of an agency, including consumers, families, managers with a variety of responsibilities, direct service staff, and clinicians, as well as a representatives of the Board of Directors.

General Methodology:

Method: The *Council on Quality and Leadership in Supports for People with Disabilities* (see www.thecouncil.org), formerly known as The Accreditation Council, is one of the largest organizations in the United States providing external review and accreditation of developmental disabilities agencies. Another organization providing external accreditation is the CARF--The Rehabilitation Accreditation Commission (see www.carf.org). Both organizations initiate provider agency self-assessment processes which are then followed by an external review. Self-assessments and external reviews are interleaved with provider quality assurance activities. Both processes entail extensive contact with and interviews of primary consumers of services, and their families, as well as many direct service staff, clinicians, and agency managers. The length of time to suitably complete self-assessments and external reviews will be directly related to the span of activities of the agency and the number of people it serves.

Individual consumer interviews (i.e., personal face-to-face interviews) have increased greatly in importance during the past decade in gathering information to be used in accreditation decisions, and much of the summary of outcomes achieved by provider agencies is based on grouping outcomes first identified on a person by person basis. Interviews often take 1.5 to 2 hours per person, and surrogate responses, by family members or advocates, are accepted if a person is not able to respond to questions. Both The Council and CARF encourage agencies to evaluate changes in performance over time, and to compare their performance to other comparable provider agencies and to national trends (www.thecouncil.org). For a more complete understanding of the approaches and measures used by The Council and CARF, readers are strongly urged to visit their respective web sites.

The Council has organized a series of 25 outcome measures in seven categories, based on factor analysis: affiliation, attainment, autonomy, health, identity, rights, and safeguards (Gardner, Nudler, & Chapman, 1997). These outcome measures are shown at the end of this section. CARF utilizes principles (e.g., www.carf.org/Assisted Living/Indicators.htm) that address some of the same general concerns as the outcomes developed by the Council, but where CARF focuses on provider activity, The Council focuses on consumer outcomes. Thus, for Council's process may be especially suitable for addressing organizational concerns about individualization of services and how individual differences in needs for supports and services are being addressed.

**COUNCIL ON QUALITY AND LEADERSHIP IN
SUPPORTS FOR PEOPLE WITH DISABILITIES (1997A, 1997B)**

PERSONAL OUTCOME MEASURES

IDENTITY

People choose personal goals
People choose where and with whom they live.
People choose where they work.
People have intimate relationships.
People are satisfied with their personal life situations

AUTONOMY

People choose their daily routine.
People have time, space, and opportunity for privacy.
People decide when to share personal information.
People use their environments.

AFFILIATION

People live in integrated environments.
People participate in the life of the community.
People interact with other members of the community.
People perform different social roles.
People have friends.
People are respected.

ATTAINMENT

People choose services.
People realize personal goals.

SAFEGUARDS

People are connected to natural support networks.
People are safe.

RIGHTS

People exercise rights.
People are treated fairly.

HEALTH AND WELLNESS

People have the best possible health.
People are free from abuse and neglect.
People experience continuity and security.

Organization-Wide Management Information System for Self-Assessment

This option for self-review entails establishing a management information system, based on data collected about individual consumers, and focusing on the core issues of person centered planning, choice, and community integration. It is modeled after, and uses instruments developed in the course of the Willowbrook Futures Project. This project was conducted by a team of OMRDD researchers during the mid-to-late 1990s in New York City, in which person centered planning was implemented with selected Willowbrook Class members. The forms discussed under this option represent a refinement of the forms used in that project.

Participants: Recommended participants in the management information system development are agency service coordinators, consumers, and family members. Depending on the types of services in which a person participates, the key informant for completion of protocols would be the service coordinator, the consumer, or family members.

General Methodology:

Method: This approach uses a survey data collection method, relying on key informants, to obtain information regarding the status at a given time of provisions in agency daily operations consistent with person centered planning, offering choices to consumers and honoring these choices, and assuring participation and integration into the community and social networks.

Meeting Schedule: In the Willowbrook Futures project, protocols were completed every six months, but it may be more feasible for some organizations to collect information annually. Generally, a period of one year between completion of protocols will allow agencies time to consider and address any concern identified in the earlier survey, and provides a reasonable timeframe to implement change and confirm the extent to which such changes have been valuable or effective.

Time Commitment: After getting practice completing several forms, the average time required to complete the longest of several protocols is about 20-35 minutes. Depending on how many different types of services are included an agency's implementation of the management information system, a total of three surveys may be completed for an individual consumer, but in most cases, two will be completed, for different types of services a person utilizes. When these tasks are combined with periodic (quarterly, semi-annual, or annual) reviews, when much of the needed information will be readily at hand, the additional time required to collect the information will be minimized.

Organizing Framework: The content of the surveys is oriented primarily around the extent to which person centered planning, choice, and community integration are occurring in the lives of consumers. Four surveys address these concerns:

Residential Habilitation Outcome Indicators Survey - The Res Hab Survey captures information on the residential habilitation services that a consumer receives and activities supported by res hab staff. The survey captures information on person centered planning, choice and community integration. Service Coordinators fill out the survey. Although originally designed for use in res hab services, this survey can be used to gather data in any residential setting, certified or uncertified.

Day Habilitation Outcome Indicators Survey - The Day Hab Survey captures information on the day habilitation services a consumer receives and activities supported by day hab staff. Specifically, the survey captures information on person centered planning, choice and community integration. Service Coordinators fill out the survey. This survey can be used to gather data in any day service, day program, or pre-vocational or vocational setting.

Family Support Services Outcome Indicators Survey - The Family Support Services Survey captures information on planning and delivery of Family Support Services. Service Coordinators or Family Support Coordinators fill out the survey either by phone or in person with family members. This survey can be used to gather data for anyone who is participating in one or more family support services.

Consumer Outcome Indicators Survey - The Consumer Survey captures information on how the consumer feels about the services he or she is receiving. Specifically, the survey captures information on activities, service delivery, and choice. Consumers fill out the survey with the assistance of a service coordinator. Each person completing the survey must fill out a copy of a consent form before completing the survey. This survey can be used with people who are receiving any type of service. A copy of a Consumer Survey follows the description of this self-monitoring approach. Copies of the other surveys may be requested from OMRDD by calling 518-474-4904 or writing to:

Bureau of Planning and Service Design
OMRDD
44 Holland Avenue
Albany, NY 12229-0001

The Person Centered Planning section of each of these surveys assesses how frequently and to what extent key person centered planning principles are used to affect a consumer's life. It does so by gathering information on: how a consumer's interests and goals drive his or her activities and supports; the degree to which community inclusion occurs; the size of groups involved in doing activities; and involvement of those who know the consumer well.

The Choice section of each of these surveys assesses how a consumer's choice influences his or her life on a daily basis. Specifically, this section looks at choices made regarding: home, relationships, appearance, day activity, and recreation and leisure.

The Community Integration section of each survey assesses how frequently consumers take part in and make use of community resources for various aspects of their lives. Community aspects considered in this section include: recreation, housing, natural supports and social relationships, shopping, banking, entertainment venues, restaurants, transportation, and places of worship. The Community Integration section looks not only at frequency of community integration, but also at the conditions under which community resources are used. In part this is done by taking a look at the size of the group that makes use of the community resource. In order to be recorded, activities must take place at a community location, that is, a place where the majority of people present do not have developmental disabilities and the primary purpose of the place is not to provide services for people with disabilities.

CON

CONSUMER OUTCOME INDICATOR SELF-SURVEY

This form is to be completed by consumers, with the support of the service coordinators, if needed.

CONSUMERS: PLEASE READ AND SIGN THIS SECTION BEFORE COMPLETING THE SURVEY

INSTRUCTIONS: Please read these instructions and sign your name before you answer any questions in this survey. If you have trouble reading this, the instructions will be read to you. You do not have to answer these questions if you do not want to.

HERE IS THE REASON FOR THE SURVEY- We are doing a study to find out what you think about the services you are getting. We are trying to find out if you like the services and if they are helping you. We would like you to answer questions about your job, your home life and what you do in the community. There are no right or wrong answers. You cannot pass or fail, because we want to know your opinion and your feelings. If you agree to participate in this study, we may ask you to **fill** out this form again some time in a few months, or perhaps one year. There are no risks to you in answering the questions. A few people will be able to see your answers, but they cannot tell anyone without your permission. Your answers will be kept confidential.

PARTICIPATION IN THIS STUDY IS UP TO YOU.

IF YOU AGREE TO TAKE PART IN THIS STUDY, PLEASE COMPLETE THE FOLLOWING-

I, _____ (your name) state that I am over 18 years of age and that I agree to take part in this study. _____ (staff member) has fully explained to me the risks involved and the need for the research. He/She has informed me that I may stop participating at any time without anything bad happening. He/She has offered to answer any questions that I have about the study and I understand that I will be given a copy of this consent form. I freely and voluntarily agree to take part in the research study.

_____(Signature or Mark of Subject) _____(Date)

_____(Signature of Witness) _____(Date)

Today's Date- _____

Your First Name- _____

Your Last Name- _____

Do you get-

Residential Habilitation YES NO

Day Habilitation YES NO

Both YES NO

PERSON-CENTERED PLANNING

Definitions for frequency rating for questions I- 19:

Almost Always = nearly 100% Sometimes = about 50% Almost Never = nearly 0%

If you believe that a question does not apply to you, please mark *Almost Never*.

QUESTIONS BEGIN ON THE BACK OF THIS PAGE

Indicate your answers by marking the choices shown below each question.

1. Do you like the activities you do every day?

Almost Always Sometimes Almost Never

2. Are you in a group of people when you receive services?

No Yes

If yes, how many other people are in these groups (not including staff)?

1-2 3 or more

3. Do you choose the services you get?

Almost Always Sometimes Almost Never

4. Do people make important decisions about you without asking your first?

Almost Always Sometimes Almost Never

5. Are important things that affect your life discussed with you at meetings?

Almost Always Sometimes Almost Never

6. Do you talk to other people about your feelings about your daily activities?

Almost Always Sometimes Almost Never

7. Do you talk to other people about your feelings about your home life?

Almost Always Sometimes Almost Never

8. Do you talk to other people about your feelings about your friendships?

Almost Always Sometimes Almost Never

9. When you tell staff that you do not like something, do they make the changes that you want?

Almost Always Sometimes Almost Never

Comments:

CHOICE

10. Do people talk about different ways of doing things before you have to make an important choice?

___ Almost Always ___ Sometimes ___ Almost Never

11. Do you have the chance to try different things before making choices?

___ Almost Always ___ Sometimes ___ Almost Never

12. Do you make important choices about your home (e.g., how much space you need, the type of furniture you like, what goes on the walls, choice of roommates, pets)?

___ Almost Always ___ Sometimes ___ Almost Never

13. Do you make important decisions about your work (e.g., where you work or what you do at your job)?

___ Almost Always ___ Sometimes ___ Almost Never

14. Do you make important choices about your friendships (e.g., who you have as friends)?

___ Almost Always ___ Sometimes ___ Almost Never

15. Do you make choices about when to eat and what food to eat?

___ Almost Always ___ Sometimes ___ Almost Never

16. Do you make decisions about the way you look (e.g., choosing what clothes to buy or wear, when you take a bath or shower, how your hair is cut)?

___ Almost Always ___ Sometimes ___ Almost Never

17. Do you decide when to go to bed?

___ Almost Always ___ Sometimes ___ Almost Never

18. Do you get to do what you want to do in your free time?

___ Almost Always ___ Sometimes ___ Almost Never

19. Do you smoke, drink alcohol, overeat, drink coffee and read adult magazines (like Playboy or Playgirl) if you choose to?

___ Almost Always ___ Sometimes ___ Almost Never

20. Do you feel you have the chance to meet people and make new friends?

___ Almost Always ___ Sometimes ___ Almost Never

Comments:

COMMUNITY INTEGRATION

21. During the past 14 days, did you ...

Go to a bank?

Yes or No	
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N

Go to a hair salon or barber?

Play sports or exercise?

Go to see sports events?

Eat in a restaurant?

Go to a movie?

Go to a religious service?

Go to a concert, show, fair, or festival?

Go to a museum or library?

Go to a store to rent a video?

Go to a market or store for groceries?

Go to a store or mall and buy something for yourself?

Go to a club meeting?

Go to a party, picnic, or barbecue?

Go to an educational class?

Go to a work site?

Yes or No	
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N
Y	N

TO BE COMPLETED BY STAFF WHO ASSISTED, OR BY THE AGENCY SURVEY COORDINATOR

Please mark one:

_____ This consumer completed this questionnaire alone (or with physical assistance, limited to marking his or her answers on the form)

_____ This consumer completed this questionnaire with additional assistance beyond physical assistance, including explanation of questions or items and interpretation by staff of his or her statements.

_____ A family member, friend, or advocate completed this questionnaire on behalf of the consumer.

Staff Person's Last Name- _____ First Name- _____

THANK YOU FOR YOUR ASSISTANCE WITH OUR PERSONAL OUTCOMES STUDY

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