

Consumer Information Files, Independent Living Plans, and Service Coordination for Centers for Independent Living

Prepared by:

**Marilyn Hammond ♦ Judith Holt ♦ Darrell Lynn Jones
Deb Langham ♦ Amina Donna Kruck ♦ Roger Howard
Darrel Christenson ♦ April Reed ♦ Paula McElwee
Jeff Sheen ♦ Patricia Yeager**

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Independent Living Research Utilization
1333 Moursund
Houston, TX 77030
713.520.0232 (Voice and TTY)
713.520.5785 (Fax)
<http://www.ilru.org>

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Project Director: Richard E. Petty
Senior Editor: Darrell Lynn Jones
Publications Staff: Brooke Curtis, Carol Eubanks, Sharon Finney, and Dionne Rauseo
Individualized Technical Assistance: Free, timely, and individualized technical assistance is available to you and your CIL or SILC as a service of the IL-NET. Email Paula McElwee, IL-NET Technical Assistance Coordinator, at paulamcelwee.ilru@gmail.com.

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Introduction

Centers for Independent Living (CILs) provide vital services that impact individuals with disabilities, service providers, local communities, and overall systems. CILs make it possible for individuals with disabilities of all ages to live more independently. CILs strengthen support systems and increase the accessibility of communities. CILs also shape and improve local, state, and national disability policies.

The CILs program purpose, according to Title VII, Chapter 1 of the Rehabilitation Act, as amended (the Act) is

...to promote a philosophy of independent living, consumer control, peer support, self-help, self-determination, equal access, and individual and system advocacy, in order to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and their integration and full inclusion into the mainstream of American society.

To accomplish their mission, CILs operate from a set of core values that emphasize individual choice and self-determination. To put these values into practice, there are key elements that characterize CILs. These elements include:

- Consumer control over policy and management decisions
- Consumer control over service objectives and methods
- A cross-disability emphasis
- A community-based and community responsive approach
- Peer role modeling in service delivery
- A range of services
- Systems advocacy and systems change efforts
- Open and ongoing access to services by consumers¹

Effective service coordination is another element that is essential for CILs. Service coordination is much more than “coordinating services.” It is a comprehensive approach that begins with providing effective and timely information and referral (I&R) and identifies needs and priorities, collaboratively develops goals and objectives, creates and maintains Consumer Information Files (CIFs), problem solves as barriers are identified, documents all activities, complies with regulations, conducts systems

¹ M.A. Lachat, The Independent Living Service Model (Center for Resource Management, Inc., South Hampton, NH, 1988).

advocacy, and more. All of these activities must be accomplished within the context of sound management practices in all areas of CIL governance and operations. CILs must have active internal controls necessary to assure that they are managing their grant award in compliance with Federal statutes, regulations, and the terms and conditions of the award. Effective records management and reporting practices are fundamental areas that provide a solid foundation of accountability to the CIL's consumers, communities, and funding sources. This manual will help staff learn more efficient and effective ways of accomplishing service coordination, creating accurate consumer records, fostering consumer control, and engaging in advocacy, which will support high quality services to CIL constituents.

All activities must also be accomplished within the context of the guiding principles of consumer control and direction. CIL staff need knowledge and skills to provide coordination that is useful, meaningful, and respectful of the consumer's preferences and priorities.

Previous approaches to serving people with disabilities were based on the belief that the consumer's disability was the "problem" that needed to be "fixed." The Independent Living Program focuses on fixing the barriers within the environment or the overall system. This manual will integrate the IL model of systems advocacy with self-direction, consumer control, and peer support in the context of good practices. It will emphasize effective service coordination, practices and services, documentation, and individual and systems advocacy.

As new opportunities arise, such as changing federal policy, documentation of effective practices and consumer services will become increasingly important. It's time to bring consumer direction and peer support models into a new level of maturity. No other agency provides similar services under the IL consumer control model. For this reason, CILs should be better equipped to provide service coordination within and among the core services, and link with other community services and programs.

There are five chapters in the guide:

1. Chapter 1: **Service Coordination and Consumer Control** – includes setting the stage to enhance consumer control; assisting consumers with determining their own best solutions; empowering CIL administration, staff and consumers; providing seamless and interconnected services; identifying the best approach to connect consumers to services; and developing agency relationships.
2. Chapter 2: **Core Services** – includes why I&R is a core service; staffing I&R services; completing documentation and tracking data; providing peer support for consumers and staff; offering practical IL skills training; conducting individual and systems advocacy; and facilitating transition of youth and institutional transition and diversion.
3. Chapter 3: **Interviewing and Assessing Needs** – describes key elements of an effective interview that supports consumer control, uses a strengths-based approach, and identifies needs; and the documentation required in the CIF.

4. Chapter 4: **Goal Setting with Consumers** – includes how to help consumers consider, identify, write, and reach their IL and community integration goals in significant life areas; the reporting requirements of the annual program performance report (PPR); the significance of goals in meeting federal requirements for the CIF; and the importance of planning activities and utilizing core services to achieve goals—determining what needs to be done, when it needs to be done, and who is responsible.
5. Chapter 5: **Consumer Information File Documentation** – includes federal requirements and useful practices for record keeping and reporting, related requirements for the annual PPR of services and activities, useful practices for gathering consumer information, developing Independent Living Plans, and maintaining complete and accurate records.

Service coordination practices will be described in the context of assisting consumers with accessing the services they want and need. Sections focus on the I&R process, interviewing, goal setting, service planning (IL plans), service coordination, advocacy, and follow-up. From the moment an individual with a disability contacts the CIL until the CIF is closed, service coordination is the thread that connects all the various activities and supports consumers to reach their goals.

Sources

The guidance given herein is based on the following three sources:

- Federal regulations, guidance, and tools
- Requirements of the annual PPR
- Useful practices that are recommended because CILs have found them worthwhile and effective

Regulatory references are from the Act and the Code of Federal Regulations (CFR) Title 45, Part 1329. The PPR requirements that are included in a CIF are also identified and included in a table at the end of Chapter 5.

A Note on Terms

The following key terms are used in this manual:

Consumer. Many CILs were founded during a time when consumer awareness was becoming important to various advocates in our country. Leaders in the IL movement sought a term that would reflect how empowered people participate fully in the decisions that affect their lives. The term “consumer” was seen as connoting personal control and awareness and was adopted widely among CILs.

Consumer Information File: The term “Consumer Information File” refers to the record maintained for each individual receiving services (other than information and referral) from a CIL.

IL Specialist: Many CILs use the job title “IL Specialist” to designate staff members with the primary responsibility to initiate and maintain the Consumer Information File. We have chosen this term for the manual because of its use by many centers. Other CILs use terms such as IL Coordinator, Advocate, IL Generalist, or Peer Advocate.

Goals: The word “goals” is used to reflect the requirement of the Act: “INDEPENDENT LIVING GOALS.—The center shall facilitate the development and achievement of independent living goals selected by individuals with significant disabilities who seek such assistance by the center.”²

² Sec. 725. Standards and Assurances for Centers for Independent Living. (b)(3)

Chapter 1. Service Coordination and Consumer Control

Chapter Objectives

In this chapter you will learn:

1. Ways to support consumers in determining their own solutions.
2. Why CIL administration, staff, and consumers need to be empowered.
3. Why CILs should strive to provide seamless services.
4. Effective approaches to connect consumers to services.
5. The importance of developing good agency relationships.

Setting the Stage

Consumer control may not just happen naturally. It may take conscious effort to set the stage and use the techniques that will prove most beneficial. Enhancing consumer control is a process that includes:

1. Effective interview techniques
2. Strength-based and open-ended questions
3. Encouraging and empowering consumers to lead
4. Meeting and communicating often
5. Troubleshooting potential problems

Consumer control is a CIL basic principle that will increase successful outcomes. Consumer control can be continually fostered while assisting consumers. This chapter will discuss additional practices that will enhance consumer control throughout the service delivery process.

Assist Consumers with Determining Their Best Solutions

In the spirit of good customer service, CIL staff may quickly answer questions or find potential solutions, but it's actually not in the consumer's best interest to do so. A more beneficial approach is to help consumers identify, study, and evaluate different alternatives so that they can make an informed choice. It's usually better to consider the positive and negative consequences of more than one alternative, option, or answer.

"Nothing About Us Without Us"

Well-meaning social workers, parents, and family members often ask CILs if they will persuade their child, spouse, or client to participate in certain programs, because they feel that it would be beneficial for them. Indeed, CIL involvement would most likely have a significant impact, but only if the consumer desires to participate. Just like anything else, the relationship is not going to work without the consumer's ownership and buy-in. In these kinds of situations, CILs can encourage family members, professionals, and consumers to come in together and discuss CIL services, so that the consumers can be shown as the leaders in the process and enabled to make their own decisions.

Empowering Consumers and Staff

Empowerment is a central tenet of independent living. Empowerment at the CIL can occur at every level, from the top down, by giving people knowledge, tools, freedom, and whatever level of authority is appropriate to the position they hold. The CIL board can empower the executive director, who can empower program managers, who can empower frontline staff. CIL frontline staff who are treated as professionals and trusted to do the job that they've been hired to do will be in a better position to facilitate the empowerment of consumers. It is difficult for micromanaged staff to act in an empowered way. When administration, staff, and consumers are all empowered, it shows an organization-wide commitment.

A CIL is one of the best places in a community for people with disabilities to learn about empowerment and acquire IL skills. CILs are places where people with disabilities can learn to take control of their own lives. A CIL is a resource where consumers are asked about their heart's desire, and then works with them to fulfill those dreams.

The services and policies of CILs are consumer-led and consumer-driven. As required by law, people with disabilities make up more than 50% of employees in decision-making positions and in staff positions; and people with significant disabilities make up more than 50% of the board of directors. Consumers make decisions about the organization and help set advocacy priorities. Consumers determine for themselves what their goals are, with staff guidance and assistance.

In an empowered CIL, management and employees continually work together as a team to improve services. Some type of mechanism or procedure should allow all staff to take ideas and make suggestions to their immediate supervisor. Employees rise to higher level positions when they think about the whole organization, not just their job. Taking personal responsibility benefits both the employee and the organization.

Strive for Seamless Service Delivery

The social service "runaround" is frustrating for anyone who experiences it. People feel irritated when they are transferred on the telephone from extension to extension, only to be put on hold, and then eventually hung up on. Having to come back on a different day or time to an appointment—after scheduling transportation, child care, and personal

care—is expensive and inconvenient. Sometimes the resources that people are provided are not current. Consumers may find out that an agency doesn't provide the needed services, or that they used to provide those services and don't anymore. Another fairly common frustration is calling a resource given by another resource only to get referred back to the first resource.

CIL services are improved when employees continually think about how to avoid service runarounds and make things easier for consumers. Excellent CIL services are as seamless and interconnected as humanly possible. Having less stress and frustration increases consumer satisfaction, well-being, connection to services, and ultimately, independent living.

Seamless delivery usually starts with I&R, the gateway to all CIL services. Information is exchanged when a consumer initially contacts the I&R staff. While the caller may only inquire about services, a skilled staff person uses open-ended questions, combined with good interview skills, to determine what a consumer may need.

Connecting Consumers to Services Quickly

The CIL connects consumers to needed services so that they can reach their independent living goals. Consumers may benefit from CIL services, activities, or events, and/or community activities outside of the CIL. The sooner consumers get connected to needed services, the sooner they can work on obtaining their goals and increasing their independence.

It matters how internal referrals are handled within the CIL. The consumer can choose the referral option that feels the most comfortable: contacting referrals directly, being connected to referrals, or having staff contact referrals to obtain the information. No matter which option they choose, consumers ought to be connected to the right person quickly. The CIL staff person can then follow up to ensure that the connection occurred and that the right information was obtained. When consumers show up without an appointment, they need to be connected right away to a staff person, or at the very minimum, leave with a scheduled appointment.

Meeting with All Parties

It will be helpful for everyone to initially meet in person when consumers are referred to another agency or to a different department. Before the meeting, the consumer should know with whom they are meeting, what's going to happen, what is expected of them, and what their responsibilities are. Planning activities and trouble-shooting issues with other people and agencies will enhance successful consumer outcomes.

Developing Agency Relationships and Learning Services

It's a good idea for CIL staff to take the time to visit other agencies. By knowing eligibility criteria and the way to access services, consumers can be referred in confidence. Contact agencies, if possible, before consumers are connected to ease the transition. Follow up if the person was denied services, even though he or she had met

agency criteria, to find out what happened. Perhaps the application was missing information, or there may have been a misunderstanding.

Developing relationships with people working in other service agencies makes it easier to collaborate and work together when difficult situations or issues arise. The first step could be educating other agency staff about CIL services. Agencies can also be asked to provide training to the CIL. Examples of service agencies include any state agencies, county entities, transportation agencies, Aging and Disability Resource Centers (ADRCs), aging groups, children's services, rehabilitation services, housing agencies, and disability organizations.

In addition, joining state, local, and national task forces, coalitions, committees, and groups that are working on issues that affect people with disabilities may enhance how services are provided through networking. These groups provide the opportunity to build relationships to work together for the common good. Some examples of issues include long-term care, assistive technology, affordable/accessible housing, nursing home transition, and violence prevention. There may be others in the local disability community besides staff who can effectively serve on these councils or organizations. Assisting emerging leaders in gaining skills to participate as committee or council members can be worthwhile to all.

Sometimes conflicts or disagreements arise in the community for consumers. It's worthwhile to contemplate situations from the other agency's point of view or perspective. Considering another perspective may provide a new and better alternative. A different viewpoint can also improve the chance of successful mediation and positive advocacy outcomes.

Chapter 2. Core Services

Chapter Objectives

In this chapter you will learn:

1. Reasons why I&R is a core service.
2. The importance of utilizing other resources.
3. Why documentation and data are vital for reporting and funding.
4. The benefits of peer support for staff and consumers.
5. Elements of independent living skills training.
6. The impact of individual and system advocacy.
7. The three aspects of transition services.

Core Services Are the Vehicles or Outputs to Achieve Goals

In terms of the Consumer Information File (CIF), the core services (advocacy, I&R, life skills training, peer counseling/support, and facilitating transition) are not considered goals. The core services are the vehicles or outputs that enable consumers to work towards and achieve their goals, leading to desired outcomes. For example, most consumers would not choose to list peer support as a goal. However, peer support and/or IL skills training might be used as a way to reach a goal of using the public transportation system which might lead to better integration into community life.

The goals, determined by the consumer, should incorporate one or more of the IL core services or other optional independent living services in their action steps. For the transportation goal example, peer support and IL skills training could be listed in two different action steps. Determining and planning the needed actions, or road map, to complete consumer goals is critical. More details on developing a road map to achieve goals are provided in Chapter 4. The quality and quantity of results depend on the specific actions that are planned and completed. Staff can assist consumers with the various steps needed for successful outcomes.

Information and Referral

Why Information and Referral Is a Core Service

Service coordination starts with information and referral (I&R). I&R is sometimes viewed as being less important than the other core services. There are several reasons why I&R is important and included as one of the core services. First, it's a primary means of promoting consumer empowerment. There is no question that knowledge is power. The

more people know, the more effective they can be in making decisions and managing their own lives. Knowledge supports an individual's capacity for self-determination and can help consumers gain the needed skills to act on their own behalf. The Alliance of Information and Referral Systems (AIRS) states that I&R provides education, affirmation, collaborative planning, and problem-solving. I&R provides guidance for consumers on how to navigate the complex and confusing service system.

Second, it is the first point of contact for the majority of consumers. I&R is the gateway and link to all other CIL services, making this function critical. Since I&R is a priority, it is important that the first CIL person a consumer speaks to is competent, professional, welcoming, and knowledgeable. If the I&R person is not helpful, callers will not be connected to the CIL and the services they need to increase their independence.

Third, this staff person must have a sound understanding of CIL services, available community supports, and how to effectively access them. A new staff person will require training and practice to get grounded and proficient in the I&R position.

Fourth, I&R Specialists must possess strong customer service skills. Providing good customer service starts with someone who has a positive, energetic style; is understanding and caring; connects well with others; and provides accurate and relevant information. An effective I&R Specialist combines comprehensive knowledge with excellent customer service.

Utilizing Other Resources

I&R staff must have a good working knowledge of CIL programs and services, as well as community agencies, to provide excellent assistance and knowledgeable referrals to consumers. Effective I&R means courteously referring people to the right place at the right time.

When a difficult situation doesn't have a foreseeable resolution, it's helpful to consult with other experienced staff, as well as knowledgeable people and agencies outside of the CIL. Let the consumer know that all possibilities will be investigated, but there may or may not be a solution. There is a better chance of resolving tough situations if you brainstorm with other people and agencies.

Following Up in a Timely Fashion

Conducting follow-up is just one more step in providing good customer service. Timely follow-up is a simple way to show consumers that the CIL cares. An easy way to accomplish this task is to ask a skilled, dedicated volunteer to complete regular callbacks to make sure that the consumer's needs were met. Some of the follow-up questions could include asking whether the CIL provided good customer service, and if the consumer received needed services in a timely manner. Additional questions may ask whether any additional information is needed and how the CIL can help the consumer further. When CILs consistently follow-up and ask about current needs, more consumers will get their needs met and will spread goodwill to the rest of the community.

Keeping Good Records and Tracking Data

Keeping track of I&R services is done differently in different CILs. Some CILs keep a tick sheet next to the phone, which lists the topic areas on the PPR. Topics are quickly marked as calls occur, so that all contacts are correctly counted. Some CILs may ask employees to enter I&R data electronically on a daily basis. Reporting should be done promptly, both to increase accuracy, and to ensure that actions are not overlooked. Then at the end of the month CIL staff should review their records to make sure they are giving themselves credit for all their activities. Encourage staff to discuss their activities and services during staff meetings.

Some CILs state that housing, employment, financial assistance, and health care are the top four categories in which consumers request services. By documenting the calls in each category every month, trends can be spotted. These trends may lead the CIL to organize systems advocacy and/or community action. Collecting basic demographic data, such as zip codes, makes it possible for CILs to notice where issues arise and can further strengthen systems advocacy.

Effective record keeping and data management assure better accountability, both within the CIL and the community when referrals are made. Accurate records and data can facilitate long-term planning, resource development, and effective allocation. They can provide verifiable data for funding requests, grant proposals, and policy initiatives.

As mentioned, tracking data can identify needed advocacy issues. For example, if a CIL made 23 consumer referrals to an agency that provides energy assistance, tracking may show that only six people actually received the needed energy assistance. Without this information, the CIL would probably not be aware of the problem. Further investigation will establish whether the applicants were denied because of changed eligibility requirements, the applications were incomplete, or because new staff at the energy assistance office excluded eligible people. The CIL can then contact energy assistance to ascertain whether its service system and application process are completely understood, if applications need to include more verification, and that eligibility determination is being done correctly.

The following ILRU Web page has examples of CIL I&R and other forms, and other resources: <http://www.ilru.org/resources-cil-core-services>.

Staffing I&R Services

There are usually two main ways that CILs organize staff to provide I&R services. One is the shared approach where all staff at the CIL provide I&R. This approach can be very flexible if each staff member has been cross-trained and has the ability to complete all the initial activities satisfactorily—which means that either the I&R is successfully concluded or that the consumer is linked to another knowledgeable staff person. This approach empowers staff because everyone has a greater knowledge base about available services within the CIL and the community. The downside is that this approach can lead to inconsistent I&R services. Staff will vary on both their interest in I&R, as well as their ability to provide quality I&R services.

The second approach is more specialized, with one or more staff members dedicated to the I&R core function. The staff member(s) is usually more highly trained and serves as a resource for other staff as well as consumers. It is important that specialized I&R staff are knowledgeable about an array of CIL and community resources. I&R staff must also provide good customer service. In addition, I&R staff need to understand and apply the independent living model and philosophy.

Sometimes, CILs consider an I&R Specialist as an entry-level staff position. In reality, an I&R Specialist should be a position that other staff aspire to once they acquire a solid level of experience and knowledge. That doesn't mean that a new staff member can't provide high quality I&R with the right skill set, training, and mentoring from experienced staff over a period of time.

When I&R Is More than I&R

Since there is no hard and fast rule, CILs often address this issue on a case-by-case basis. Consider the following parameters in deciding when I&R goes beyond I&R:

- a) The significance and complexity of the request
- b) The number of differing requests that the person has
- c) The need for one-on-one assistance to walk the person through the situation

Single complex requests require long-term planning (and a CIF) if consumers are going to have a chance to succeed. In addition, consumers are not likely to receive the needed services to fully increase their independence, and the CIL won't receive the appropriate credit for all that is being done if multiple requests over a period of time are classified as strictly I&R.

Peer Support

Peer counseling and support is both a core service and a central principle of IL philosophy. It is considered an ongoing service and requires that a CIF be opened for the consumer and that one or more goals be set. Peer support helps strengthen consumer trust, knowledge, control, and independence. Peer support enables CILs to function much more successfully. Being a peer mentor to others can also be beneficial, fostering feelings of fulfillment, accomplishment, and friendship. Peer mentoring and support are vital for both consumers and new CIL staff.

People with Disabilities Are Experts on Living with a Disability and Navigating the System

Peers are the experts on living with different disabilities, finding information, and making adjustments and accommodations. A person with a newly acquired disability may especially benefit from interaction with peers. For instance, individuals with spinal cord injuries can help peers avoid pressure sores and urinary tract infections, select the best equipment, and find resources. Individuals with a psychiatric disability may feel more hopeful after working with a peer mentor that is living effectively with their disability.

Peers with developmental or intellectual disabilities can provide friendship and support. Peer mentors also often provide information about available services, participating in the community, and recreational opportunities. Whatever a peer has found helpful or useful in their life, the person they are mentoring may appreciate as well.

Joining a peer support group and/or working with a peer mentor can help consumers develop a new perspective, gain skills in living with a disability, and increase their understanding of consumer control. Peers can provide the nitty-gritty of how to receive services through local systems. Teaching people how the system works provides the consumer with more power and choices.

Staff Peer Support and Mentoring

Mentors make a big difference in helping new staff become more knowledgeable and learn the ropes. An experienced peer mentor can provide expert guidance and answer questions. In addition to mentoring, new CIL employees need to go through training, and observe other experienced staff in action, so that they can become an effective guide for their consumers.

Mentors can emphasize the importance of reliability. It is a trait that all staff should have. CILs should be the one place that consumers can depend and rely on.

Good observation skills are part of conducting a consumer-driven discussion to discover the consumer's strengths, goals, and barriers to success. A good listener takes accurate notes and documents all relevant activities. Mentors can help new staff understand what accurate documentation means for reports and funding to help ensure completion.

Practice, Practice, Practice

It is helpful for new staff to practice interviewing, opening up a new consumer file, writing the goal(s), and doing everything else from beginning to end with their peer mentor. Constructive suggestions can be offered afterward. Additional training can be provided where needed. Completing a substantial amount of training will prove beneficial to staff.

Exchanging closed files with other staff members for review is an effective method for learning how to close files. Files can be returned after they are reviewed and critiqued. It will be easier to remember all the necessary steps if a checklist is included with each closed file. Staff can mark off all the documents required to be in the file, including signatures, and whether more information is needed.

Discussing Challenges in Meetings and Providing Peer Support

Regular program staff meetings are a good forum to bring up consumer barriers or difficulties and provide peer support. Some CILs list consumer challenges as a regular item on their program staff meeting agenda. Brainstorming solutions help staff work through barriers. Other staff will also learn potential solutions if their consumers face similar barriers. Remember to respect consumer confidentiality.

Independent Living Skills Training

IL Skills Training Can Be Offered in Any Area That Increases Independence

The definition for IL skills and life skills training from the PPR Report states: “These may include instruction to develop IL skills in areas such as personal care, coping, financial management, social skills, and household management. This may also include education and training necessary for living in the community and participating in community activities.”

Independent living skills training is very much connected to individuals and their goals, and warrants the opening of a CIF and the development of goals. Achieving personal freedom more easily comes when consumers have the skills necessary to make their own decisions and manage day-to-day activities. IL skills training often happens one-on-one when CIL staff are working with a consumer on a goal, such as learning to take the bus; but can take place in a variety of formats, such as workshops and small groups. Groups can be cross-disability or consist of people with the same or similar disabilities. Training may occur in the CIL, the community, or the consumer’s home; or may be offered virtually through distance technology such as Skype or Zoom. In addition to the different skill areas listed in the definition, training may also be offered on Social Security benefits management, understanding resources, communicating effectively, job interviewing, assistive technology, recreational opportunities, transportation, and other areas. Independent living skills training can be provided on any skill or topic that helps an individual with disabilities to achieve life goals.

Reporting IL Skills Training

Sometimes training on life skills leads to the development of increased self-advocacy skills, and the core services of IL skills training and advocacy/self-advocacy begin to blend together. Likewise, sometimes it can be difficult to know where I&R leaves off and a more comprehensive sharing of information through training begins. And sometimes one service can easily move toward another service, such as when discussing balancing a budget leads to providing assistance with finding employment or housing. These things are actually indicative of successful outcomes, but may raise questions about how to classify a particular service in the PPR. Each CIL needs to have its own policy about this so that all staff are reporting as consistently as possible. It can be helpful to have discussions about the blended nature of services and outcomes for this reason, but also to help staff think about consumers and the services of the CIL holistically. A truly effective center will have services that are so interconnected that they will appear seamless to a consumer. The staff, however, should be able to differentiate the service provided to meet a specific goal step. When services are blended, the goals or goal steps will help the CIL determine and report services accurately.

Many CILs offer training opportunities for family members of people with disabilities. This is also a good practice and can expand the reach of IL skills considerably. However, because family members are not consumers with open CIFs, this is not IL

skills training. Staff need to track those services separately. Many CILs record them as community activities.

Some CILs have found that calling their independent living workshops another name, such as “continuing education,” is more successful at drawing participants because a lot of people with disabilities are eager to continue their education. These same people often don’t like the idea that they may need training to become or remain independent.

Learning Can Be Enjoyable

A multimedia approach to learning often makes learning more entertaining. Interactive games can be used for training; it doesn’t have to be boring. Independence *First* in Wisconsin (<http://www.independencefirst.org>) has developed games for consumer and staff training, exercises, and workshops that they are willing to share. These games are inexpensive, easy, and can be presented by PowerPoint. Some of these adapted games are similar to *Hollywood Squares*, *Jeopardy*, *Pay Day*, *Life*, *Monopoly*, and *UNO*.

A good example is using Monopoly money to budget specific amounts for rent, food, utilities and other expenses. It allows the person to determine if there will be money “left over” for entertainment and special purchases. This game can be entertaining as well as enlightening. It works well in high school classes.

Advocacy (Individual and System)

Customizing Advocacy Training

Advocacy training should be provided at the rate that works for the individual. The new advocate can initially be encouraged to engage in the advocacy activities that they’re comfortable with. Later, new advocates can be urged to step outside their comfort zone and make additional contacts.

There are different styles of advocacy. Some might engage in a more aggressive or assertive type of advocacy, others prefer a more collaborative, instructive, and educative type of advocacy. There’s room for every kind of advocate, and every type of advocate is needed. Educating the people and agencies with which CILs work on the range of advocacy styles and projects creates a win-win situation in which all can participate in advocacy regarding important issues.

Effective Advocates Are Collaborative, Instructive, and Persistent

Advocates working on an issue, even adversarial ones, will do well if they can also be collaborative, instructive, and persistent. When they are, people will approach them because they are seen as an expert. They can be counted on as a voice for the disability community, with good connections and the power to foster relationships. An advocate may be a third-party objective participant.

Success is all about developing relationships and educating people. Building good relationships often makes it possible for issues to move forward. Sometimes support needs to be fostered where it can be found.

Teaching Advocacy to Youth

Advocacy can be taught as part of a high school transition curriculum. Advocacy classes can empower students and help change communities. For example, after taking an advocacy class, a high school student who was a wheelchair user came in with several friends who were also wheelchair users. They were concerned because the local haunted house was inaccessible. CIL staff made an appointment for them to talk with the management. The person in charge didn't think accessibility mattered because only a few people in chairs came last year. Because of their advocacy efforts, the state fair eventually required that all venues must be accessible to users with disabilities. It is empowering for young people to make a difference, especially a systemic change. Now they advocate on other issues.

Individual Advocacy Training Example

The following example demonstrates the power of individual advocacy training. A consumer who uses a wheelchair wanted to try out his grocery store's new wine bar, but it was inaccessible because of the store's stacked aisles. The accessible parking space was also full of dirt because the owner was making an outside deck. The consumer called his CIL and was encouraged to train in assertiveness, communication, and advocacy so that he could speak to the store manager with confidence. He didn't want the CIL to visit the store with him; he wanted to go in by himself. Once he developed those skills, and learned about the ADA and accessibility, he visited the store. The store owner was apologetic and said that the barriers would be removed. Within three weeks the boxes and debris were gone and he was able to participate in wine tasting. Instead of the CIL contacting the owner, the consumer learned about the ADA, and developed advocacy, assertiveness, and communication skills. His goal and progress were documented in his CIF and he was recruited for the ADA consumer advocacy team.

Consumer Advocacy Teams

Some CILs have developed effective consumer advocacy teams. These teams are made up of consumers who are interested in advocacy and eliminating barriers from the community. Consumers gather together to work on long-term care issues, transportation, employment, the ADA, and/or other disability rights legislation or laws.

Complaining in an Effective Way

Consumers can learn how to complain and take action in an effective way to resolve barriers. The following example also demonstrates the power of advocacy. A few years ago, consumers complained to Disability Rights and Resources in Birmingham (<http://drradvocates.org/>) about either how long it had taken on para-transit to get to their destination, or that their reservation had been lost. At the time, the company was making and losing reservations on Post-It notes. The CIL helped these consumers figure out how to complain effectively to the transit authority, and attend advisory councils to describe their list of no-shows or unreasonable ride times (riding for three or four hours). The process to express dissatisfaction about para-transit is through filing

complaints with the Office of Civil Rights (OCR). Many letters were written to the executive director of the para-transit, copied, and sent to the OCR. For every consumer that brought a complaint to the CIL, a complaint form went to the OCR, until a site visit was triggered from the Department of Transportation. The document that was compiled from their site visit was used as evidence in a class action suit for the CIL's consumers, resulting in free para-transit rides for one year. These documented consumer complaints significantly improved the para-transit system.

Advocating for Transit Services and Training Providers

It's a good idea to develop a relationship with the local transit company and advocate for its funding. Often concerns like transit routes being cut, or regular fare increases are under consideration. The CIL can advocate with both the transit company to improve services to people with disabilities, and with legislators or local government to keep and fund transit services. Disability awareness and communication training can be offered to para-transit and fixed route staff. Similar training can be offered to other agencies that interact with people with disabilities, such as state agencies, law enforcement, shelters, and health departments.

Advocating for Accessibility

The next example illustrates how far reaching advocacy actions can sometimes be. A few years ago, a housing developer let Ability360 in Phoenix (<http://www.ability360.org/>) know that he was building 28 units that included three or four accessible ones. When a meeting was set up, the architects were very receptive and open-minded. Ability360 looked at the blueprints and suggested ways to more effectively use the space so that it would include more accessible units, but with the same footprint, lot size, and square footage. All 28 units were redesigned to be accessible. It's most effective when advocating with businesses to know what their focal points are; to developers it's usually money. As with most businesses, they had a finite amount of money to work with. Ability360 let the developers know that now they could market to 100% of the population, because the units were accessible to everybody. The ability to lease increased tremendously. Ability360 was talking their language. It was a win-win situation. The developers did a project in Phoenix and made those 60 units accessible. When in Miami, Ability360 met with one of the reps and talked about a project in Key West. The news spread throughout their company nationally. What started in Glendale continued in Phoenix and is now having an impact in Miami. That company is dedicated and committed to accessibility. They know firsthand that accessibility benefits everyone because of their collaboration and partnership with Ability360.

Working Top Down and Ground Up

One way to connect the dots between consumer services and systems advocacy is to work from both directions. The top-down approach starts with developing or revising high-level policies and working down to improve services and access for people with disabilities. The ground-up approach starts with grassroots efforts that culminate in policy change at the top.

The following provides an example of the top-down approach. LINC in Idaho (<http://lincidaho.org/>) successfully pushed to change policy on self-directed personal assistance services in 1998. The policy resulted in a well-structured self-directed PAS program that allows people who are eligible for Medicaid and PAS to have full control over the in-home situation. An example of the bottom-up approach is when LINC started getting calls from parents with disabilities who were involved in custody battles. Idaho state statutes on parental rights, child custody, and divorce had not been updated since 1938. The law said that the court must look at and consider whether either parent had a disability when determining custody. The courts felt that disability was the deciding factor against custody, which was obviously discriminatory. LINC contacted and organized parents to advocate.

Sometimes it takes just one person to make a difference and change the law. That one person was a mother with a nine-year old child. The father didn't have contact with the child and had not paid child support. The mother had a progressive visual impairment. She was a loan officer at a bank, and doing just fine. Nine years after the birth of the child, the father had a change of heart. As soon as he realized that she was blind, he filed for and got full custody. The law was changed because of advocacy to eliminate discrimination on the basis of disability.

Legislative Advocacy

While advocacy is a core service required of all CILs, you have some flexibility in how you accomplish it, and it **can be done without lobbying**. Lobbying is a specific attempt to influence legislation or to request a specific vote on a bill.

Sometimes legislators need to be educated about the impact of impending legislation on people with disabilities, and the actions that the CIL would like them to take; **but there are restrictions on using federal money to lobby**. To participate in lobbying, most centers carve out some of their discretionary funds for the step of requesting a vote on a specific piece of legislation. As long as your lobbying expenses and time are tracked separately and not charged to your federal grants, your center can participate in lobbying.³ The other advocacy and education efforts are not only allowed, but expected as the core service of advocacy takes place.⁴

It's important for consumers to know who their city officials, county supervisors, state senators, and state representatives are, so that they can contact or visit them when there are issues. Provide training beforehand, when possible, on how to effectively write a letter, send an e-mail, make phone calls, and discuss disability rights legislation or laws to people who are in power. Speaking to legislators and other officials is very empowering for consumers and beneficial for policy makers.

It's good practice to visit elected officials at least once a year. During this visit, consumers can identify themselves as voters with disabilities in their district, and ask

³ There are limits to the amount of lobbying a nonprofit organization can engage in, set by the Internal Revenue Service. See IL-NET Sample Fiscal Policies and Procedures Handbook, pages 28-30 available at <https://www.ilru.org/topics/cil-financial-management>.

⁴ See the FAQ Allowable Advocacy Activities for Federal Grantees at <https://www.ilru.org/federal-guidance-il-program>.

about their disability agenda, including their priorities for the state, CIL, and people with disabilities. Some CILs coordinate an annual legislative day with other centers and disability advocacy organizations with prepared agendas and advocacy priorities set beforehand.

If legislation is passed, legislators should be congratulated and thanked. The relevant legislators can be asked if they will hold the signing. Advocates with disabilities, other individuals who were instrumental to the successful legislative outcome, and the press can be invited. Press releases can be prepared and disseminated through different media to publicize the issue and the signing. Legislators are usually eager to help publicize the issue.

Using Social Media

Using social media is an effective way to communicate with multiple audiences and conduct outreach, marketing, and advocacy. Often, a monthly newsletter is too slow when advocacy needs to happen. E-mail addresses and phone numbers for texts can be collected, compiled, and used to share timely information. People can be grouped into the topics that they are interested in, to avoid sending e-mails or texts on every issue.

Facebook, Instagram, Twitter, YouTube, Pinterest, LinkedIn, Blogger, and other social media platforms can be used to reach many more consumers, providers, and policy makers. Newsletters, press releases, upcoming events, services, activities, etc. can be posted on social media as well as the CIL and other websites so that more people can learn about and access them. Community heroes who have been supportive deserve recognition on the CIL website, newsletter, blog, Facebook, and Twitter. Webinars, demonstrations, and training videos can be posted on YouTube and other platforms.

Training on social media can be found at: www.ilru.org/search/node/social%20media.

Changes Take Time

System advocacy initiatives can take a long time. Just because an initiative gets defeated doesn't mean it's finished. Most issues won't change without the persistence of advocates continually working on them, often for years.

Changing policies or systems often requires taking many little steps before any progress is made. After a big defeat, it often helps to regroup with other advocates. Analyzing what could be done differently next time may help people feel revitalized and encouraged enough to continue working on the issue.

Transitioning from an Individual Issue to Systems Advocacy

The following example provides a model of transitioning from an individual issue to identifying a group issue, and then dealing with it as a systems issue. Many older veterans who were blind had applied for door-to-door transit service, but were getting repeatedly rejected. The transit staff did not think these blind veterans had disabilities because they appeared to be getting around satisfactorily. These gentlemen, who were

often gradually experiencing a loss of vision, didn't want to carry a cane or acknowledge some of their challenges. The Veterans Administration began to resolve this issue in a couple of different ways. They started encouraging people to identify themselves more clearly as having a disability. They also thought of it as a systems issue by encouraging veterans to advocate for themselves. The veterans attended public meetings at the metro system and publicly let staff know that they were improperly being denied transportation.

The example above provides one IL model of people taking power. It's important for systems advocacy to be included in all of the activities that CILs do, including documenting better, becoming more goal-oriented, assisting consumers to set good outcomes, and then helping them realize those outcomes in a systematic way.

Transition

The Rehabilitation Act, as amended (2014) expanded the IL Program to include core services that are collectively identified as "transition." The three transition components include:

- (1) Facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, with the requisite supports and services;
- (2) Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals remain in the community; and
- (3) Facilitate the transition of youth who are individuals with significant disabilities who are eligible for individualized education programs under Section 614(d) of the Individuals with Disabilities Education Act (20 U.S.C. 14149d)), and who have completed their secondary education or otherwise left school, to postsecondary life.

Institutional Transition

The independent living movement has been active in assisting individuals to get out of institutions from its beginning, including supporting the initiatives where funding can follow the person from the nursing home into the community. Independent living advocates were involved in pushing for the Olmstead decision, a Supreme Court decision that requires that individuals be allowed to choose services in the community over institutional care if they wish. Each state has its own strategy for implementing this landmark decision. Most states are not fully implementing it, and advocacy by CILs is still needed for full implementation to occur.

See "ABCs of Nursing Home Transition: An Orientation Manual for New Transition Facilitators" at <https://www.ilru.org/abcs-nursing-home-transition-orientation-manual-for-new-transition-facilitators>.

Assisting Individuals to Avoid Institutions

The second prong above that indicates centers are to “Provide assistance [to] remain in the community” is not quite as straightforward as institutional transition is. Transition is a tangible moving from one location to another. On the other hand, avoiding institutionalization may involve assistance through one service or a multitude of services and be offered as a one-shot service such as building a ramp or long-term supports through training, peer mentoring, housing location and referral, and other services. The independent living regulations state: “Provide assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community. A determination of who is at risk of entering an institution should include self-identification by the individual as part of the intake or goal-setting process.” CILs had a head start on this service, because they have always assisted with the wide range of supports that individuals need to avoid institutionalization. For ease of discussion, most IL personnel refer to this service as Diversion.

See “Who’s ‘At-Risk’? How to Determine and Address Risk of Institutional Placement to Achieve the New Core Service of Diversion” at <https://www.ilru.org/training/who-s-risk-how-determine-and-address-risk-institutional-placement-achieve-new-core-service>.

Facilitating Transition of Youth to Postsecondary Life

Many centers for Independent Living (CILs) have been serving youth and young adults for decades, assisting in preparing for transition and providing services that facilitate the transition from school and living with parents to post-secondary education, employment, and independent living. The 2014 amendments to the Act made it a requirement that at a minimum CILs must

“facilitate the transition of youth who are individuals with significant disabilities, who were eligible for individualized education programs under section 614(d) of the Individuals with Disabilities Education Act (IDEA) (20 U.S.C. 1414(d)), **and who have completed their secondary education or otherwise left school**, to postsecondary life.”

This core service includes any independent living service provided to youth with significant disabilities who:

- (A) Were eligible for an IEP while in school, and
- (B) Have left secondary school...

...that assists them in the transition to post-secondary life.

The law’s post-secondary focus does not mean that CILs can’t also serve youth who are still in school or who weren’t eligible for an IEP. CILs have always been defined as organizations that serve all age groups. However, the required *core service*—something you need to measure—is specific to the above definition. The broader definition of youth in the law includes individuals who are aged 14-24 who are still in school as well as those who have left school. For purposes of the annual PPR, the CIL must keep track of

who meets the legal definition of the core service so it can be demonstrated that this core service is being delivered. Youth who do not meet the above definition would be reported in the other appropriate service categories.

The Administration for Community Living provided helpful guidance around this topic in an FAQ distributed to the CILs on April 14, 2017

(http://www.ilru.org/sites/default/files/resources/youth_transition/ACL_ILA_Youth_Services_FAQ0417.pdf). Full on-demand trainings on youth programs are available from the IL-NET as indicated below.

Conclusion

Because youth core and other services are complex, this section has only provided an overview. You are encouraged to browse the resources below and select those that will give you and other CIL staff the in-depth information needed.

IL-NET Resources

For more information on core services, check out the ILRU resources at:

<http://www.ilru.org/topics/cil-core-services>

Resources on institutional transition are available at:

<http://www.ilru.org/topics/institutional-transition-diversion>

Resources on determining who is “at risk” and institutional diversion are available at:

<http://www.ilru.org/topics/institutional-transition-diversion>

<http://www.ilru.org/search/node/Community%20Integration>

<http://www.ilru.org/training/community-integration-holistic-approach-new-core-services-for-transition-diversion>

Resources on transition of youth are available at:

<http://www.ilru.org/topics/youth-transition>

Chapter 3. Interviewing and Assessing Needs

This chapter describes the required elements of an effective interview and provides basic guidance about the documentation required in the CIF.

Chapter Objectives

In this chapter you will learn:

1. The importance of the initial consumer interview in establishing goals and determining the actions to achieve them.
2. Key elements for a successful initial interview.
3. Strategies to support consumer control and direction in the interview.
4. How to document the interview accurately in the Consumer Information File.
5. The basic principles of a strengths-based approach to interviewing.

The Initial Consumer Interview

The initial interview lays the foundation for a productive and meaningful collaborative relationship between the consumer and the CIL.

The interview is the key to establishing specific, practical, and consumer-driven plans that will guide the actions of the individual and the CIL staff. This occurs as the individual begins the process of identifying needs and defining the goals or objectives that will address those needs.

The IL Specialist records basic information about the individual on forms used for this purpose in the interview. Eligibility for CIL services is determined and documented during the initial interview. If individuals self-identify as persons with a significant disability, they are eligible. After eligibility for CIL services is determined, a comprehensive assessment of needs is an essential next step that will identify goals that address those needs in an Independent Living Plan. Even though some consumers may choose not to develop an Independent Living Plan, (which must be indicated with a signed waiver), goals must be established and documented. Interview documentation will be maintained in a Consumer Information File that will be kept on file at the CIL.

The initial interview may be scheduled after an I&R call when it becomes clear that the individual has multiple concerns and needs that require more than a straightforward referral. Some of the basic information about the individual, such as age, address, and telephone number, may have already been secured during the first request for information. If this is the case, only a brief review of this information may be needed. In other instances, the IL Specialist may have only a name and a general concern as the interview begins. Careful documentation of the initial interview is required as the IL Specialist develops the Consumer Information File.

Creating a Welcoming Interview Setting

An initial interview may take place at the center office, the consumer's residence, another place the consumer chooses, or remotely (telephone, Skype, Zoom). A face-to-face interview is preferred. When the interview takes place in the CIL office, create a welcoming environment by addressing the following:

1. Select an appropriate location in the office for the interview, one that is accessible, comfortable, and private.
2. Minimize distractions such as office clutter, excessive background noise, and harsh lighting.
3. Eliminate odors such as fragrances or cleansers.
4. Be sure to keep your full attention on the individual. Reduce or ignore interruptions. Do not multitask by working on other activities while talking with the consumer. (This is one reason that a small conference area away from your desk might be preferable. You won't be tempted by the phone, email, or other unfinished work within your reach.)
5. Always protect individual confidentiality. A conference room or private office should be scheduled to ensure that the consumer's confidentiality is protected if your desk is in an open area of the CIL.

When the initial interview takes place outside the CIL office, work to make the interview environment as conducive to a focused and productive meeting as possible. For instance, the individual can be asked to turn down the volume of a television or radio so that everyone will be able to hear well. The seating can be arranged so that there are no distractions.

Just as individual confidentiality is protected in an office setting, the same precautions must be taken when the interview is conducted in other settings. Check in with the consumer to determine if the presence of other family members is preferred, as it is in some cultures. If not, ask the individual if it would be possible to move to a room where other people are not present. Family members, friends, or anyone else in the room can be politely asked to leave during the interview to protect privacy.

In scheduling interviews away from the CIL office, it is wise to discuss accessibility of the interview location. This will ensure that the individual and the center staff will be able to meet in a location that is accessible to both. If the individual's home is not accessible, a remote interview may be an acceptable option.

If the interview takes place on the telephone or Web, ask the individual to please find a quiet place to talk. Use a landline if possible. Cell phones are popular, but dropped calls and distortion can interfere with the conversation.

Also, a face-to-face interview can easily last an hour, but a telephone interview that lasts over 25–30 minutes is often difficult to sustain. If the interview is conducted over the telephone, a headset may be useful so the staff person's hands are free to take notes.

The Interview—Gathering Essential Information

Gathering essential information about the individual is the first step in the interview. Explain the application process and the reasons that probing questions will be asked about the consumer's circumstances, needs, and goals in the beginning of your meeting. Also inform IL applicants or consumers, authorized representatives, and service providers about the confidentiality of personal information and the conditions for gaining access to and releasing this information.

Recording information about the consumer on a well-organized initial interview or intake form will help maintain and locate important information about the consumer later on. You will likely refer to this intake form often.

Typically, CILs ask for the person's name, address, telephone number, e-mail address, age, gender, and race/ethnicity category, as well as other information tracked in the CIL information management system.

Some centers secure both a Social Security number, and a driver's license or ID number. These items can be used as unique identifiers. If they are secured and recorded, exercise great care to safeguard both current and stored individual's privacy and security.

It will be especially useful to have complete consumer contact information, including cell or alternate telephone numbers.

Obtain signatures on forms during the interview. When an interview must be conducted remotely, arrange for the individual to receive and sign copies of required forms. Other ways to procure signatures include traveling to the person's home, arranging for the consumer to come to the CIL, or mailing forms with a stamped return envelope. If forms are mailed, be sure to mark the places where signatures are required. There are also online signature programs, such as DocuSign (www.docuSign.com) or DigiSigner (www.digisigner.com) that can help consumers sign their paperwork.

Complete information about requirements for what must be included in the Consumer Information File (as well as which forms are signed by the consumer) can be found in the last chapter.

The Interview—Determining Eligibility for Services

During the first meeting determine whether consumers are eligible for services from the CIL as outlined in Chapter 5. Ask individuals about their type of disability and how it limits independent functioning. Determine with individuals how the delivery of IL services will improve their abilities to achieve or maintain independent functioning. Document the type of services/assistance requested.

If it is determined that the individual applying for services is not eligible, follow the steps outlined in Chapter 5 to notify the applicant and document the reason for ineligibility.

Provide an explanation of the availability and purpose of the Client Assistance Program (CAP), including information on how to contact the CAP.⁵

If the person requests services that the CIL does not provide, make a referral, whenever possible, to an organization or agency that can assist the individual. When making a referral, provide as much information as possible—where assistance is available, how it may be accessed, and any specific eligibility criteria, cost, or restrictions. Document the referral in the applicant’s Consumer Information File.

The Initial Interview—Areas to Explore

The assistance provided by centers for independent living must be consistent with the purpose of Title VII expressed in section 701 of the Rehabilitation Act, as amended:

...to maximize the leadership, empowerment, independence, and productivity of individuals with disabilities, and the integration and full inclusion of individuals with disabilities into the mainstream of American society...

Centers for independent living have a broader mission than many other service organizations. Even though individuals often make an initial request for assistance with a single concern, the IL Specialist can offer the opportunity to explore other life areas that, if addressed, could enhance the individual’s ability to fully participate in society. This is an important way in which CILs can realize the purposes set forth in the law.

Needs Assessment

Conducting a thorough needs assessment during the interview will enable consumers to identify their needs, concerns, and hopes, including potential risk for institutional placement. Many CILs use needs assessment forms. Some are quite simple; others are more detailed. The form can guide your conversation with consumers to areas of need and point the way to appropriate services.

The following are some points to keep in mind when conducting a needs assessment:

- As always, the consumer should drive the discussion.
- It is useful to keep discussions positive and constructive.
- Use the items or questions on a needs assessment form to prompt the individual to consider and discuss all important life areas. Consumers may not remember to bring up all their needs in an interview and the structure of the form will help.

It may be beneficial to discuss whether the CIL form being currently used provides all of the information needed to conduct an accurate and comprehensive needs assessment of the consumer’s current situation. Centers use a variety of forms which generally fall into the following four broad categories:

⁵ Rehabilitation Act, as amended, Sec. 725 Standards and Assurances for Centers for Independent Living.

1. Some forms provide an area in which the consumer simply writes down his or her goals.
2. Some forms have a separate section to identify needs (housing, communication, mobility, employment, personal care, community-based living, etc.).
3. A third option indicates which of the significant life areas needs attention with space for writing associated goals. In addition to listing each life area, detailed prompts may be provided under each area (such as social functioning—maintain regular contact with my family, maintain regular contact with my friends, make new friends, be an effective parent or spouse, make decisions for myself, plan my life so as to achieve my goals, etc.).
4. For determining and addressing risk of institutional placement, a number of CILs are using an assessment form that is tailored to identifying “at-risk” factors, such as the one developed by CILs in Texas. Their survey and on-demand training is available at <https://www.ilru.org/training/who-s-risk-how-determine-and-address-risk-institutional-placement-achieve-new-core-service>.

There isn't a right or wrong method of assessment, as long as all the consumer's significant needs in each life area are being considered, and identified. Many other different examples for applications, needs assessment, CAP, goals, closure, and more are available at: <http://www.ilru.org/resources-consumer-service-records>.

Example Categories of Needs

Some areas of need that may be covered are listed below:

- Assistive technology and information access
- Communication
- Community and social participation
- Education
- Employment (vocational)
- Housing and maintaining community-based living
- Information access and technology
- Mobility and transportation
- Personal assistance services
- Personal resource management
- Relocation from a nursing home or institution to community-based living
- Self-advocacy and empowerment

Identifying Needs

To provide truly useful support and assistance, it is essential to address both immediate and longer-term needs. Often, individuals describe their immediate needs, such as lack of income, no friends, wanting to live in a better place, or not being able to keep a personal attendant. When consumers say that they want “a better place to live,” they may actually have a longer-term need of living independently in their own home, not just finding a place to rent near a bus stop.

Discuss various areas of possible need with the consumer. Use the needs assessment form as a guide, but do not rush through the list. Deeper, longer-term needs won't be brought up unless good interviewing skills are used. The following three interview skills may seem basic, but they are particularly important to use when interviewing consumers. Each technique is discussed in more detail below.

- Ask open-ended questions.
- Be an active listener.
- Take good notes.

The Interview—Asking Good Questions

In addition to the standard questions you will ask every consumer, the interview is a chance to gather information about the consumer's needs, expectations, and hopes.

One of the recommended ways to ask good interview questions is to use open-ended questions. If individuals are asked whether they like their current living arrangement, they will respond either “yes” or “no.” A better way to gain good information is to ask the same question in an open-ended manner, such as those shown below.

- Please tell me a little about your current living situation.
- What do you like the best about your current living situation?
- What do you not like or would like to change about your current living situation?

If the person is not very talkative, gently prompt with statements such as “Please tell me a little more about that,” or “Could you please give me some more details?” Asking these types of open-ended questions will make it possible to get much more information about the individual's situation. A good dialogue may also increase understanding about which areas (housing, employment, assistive technology, etc.) that the person may want to focus on with the support of the CIL.

The Interview—Being a Good Listener

Be an active listener. During the interview listen carefully to what the consumer has to say. Focus on the answer to each question. Don't lose that focus by planning the next question or response.

Seek to understand the consumer. Make it a point during the interview to ask clarifying and probing questions. See the “Additional Resources” list at the end of this chapter for more information on interviewing.

The Interview—Taking Good Notes

Good notes are important. Capturing the key points and details of the initial interview is critical in the independent living planning process. There are a variety of ways to take effective notes in an interview, including using an interview template and checklist, writing notes on a legal pad, typing notes into a computer, or using digital recording devices. The important thing to remember is to find a note-taking method that works well and that doesn't distract the consumer or make it difficult to stay engaged with the consumer.

Find the balance between active listening and good note-taking; both are essential elements of effective interviewing. Sometimes interviewers can get so caught up in taking good notes that they stop being active listeners and actually miss important points of the conversation. Notes need not be lengthy or time-consuming. Capture the facts that convey what has happened to date and what needs to happen next.

Setting Goals

In the initial interview define goals that will address the consumer's identified needs. It is important to remember that goals address the purpose for the consumer's engagement with the CIL.

Don't confuse services with goals. For example, “getting a ramp” may sometimes be listed as the goal. The important consideration is why the consumer needs the ramp. The consumer may achieve employment, further education, or improve community or social participation. Any one of these—employment, education, or community or social participation—would then be the goal; the ramp is the means to those goals.

As noted in the earlier sections on needs assessment, encourage the consumer to think beyond their immediate need to their goals and dreams. This will be much more effective in helping the consumer to become independent and integrated in the community. Full participation and community integration are at the heart of the purpose and intent of centers for independent living. Helping the consumer think beyond the immediate need can make the consumer's experience with the CIL transformative.

Using a Strengths-Based Approach

Many organizations have found providing services through a strengths-based approach to be especially useful and consistent with independent living philosophy. A strengths-based perspective is based on the following concepts:

- Every individual, regardless of his or her personal situation, has unique strengths.

- These basic strengths can be used as a starting place to begin developing other new strengths that will support the person’s efforts to reach his or her goals and dreams.
- Often someone outside the person’s immediate environment can help point out his or her unique talents, abilities, and strengths.

IL Specialists have the opportunity to help consumers begin to recognize their individual strengths. The following are some tips on using this approach during the initial interview.

- **Ask questions in a positive rather than negative way.** For example, ask “What is working well right now in your life?” instead of, “What is the biggest problem you are facing right now?” Although this may seem like a small difference in the way this type of question is asked, the shift in language of the question can help create a powerful change in the way a person perceives his or her current situation. Helping individuals identify what worked well for them previously can help them focus on the possibility of positive change. Here are more examples:
 - What do you want to accomplish in the future?
 - What is working well that you can build on?
 - What are some creative ways that you or someone you know has addressed this problem in the past?
- **Encourage individuals to acknowledge their strengths and abilities.** Individuals are influenced and motivated by the way significant people in their lives respond to them. Consumers are often told and reminded of the things that they can’t do, which may influence the way they think about themselves.
- **Instead of thinking that an individual has a weakness in a particular area, assume that the individual has not yet had the opportunity to learn and master a skill in that area.** An important purpose of the IL planning process is to provide consumers with opportunities to learn and develop new skills that can help them succeed in achieving their goals.
- **Developing a strengths-based perspective takes practice.** Sharing your view of an individual’s strengths with him or her for the first time can be a challenging experience. Some individuals may vigorously insist that they have no strengths. If this is the case, then consider complimenting the individual for being so persistent in maintaining their position about having no strengths and wonder out loud if such persistence isn’t a strength they have relied on in other settings to stand up for themselves or accomplish a difficult task. For many individuals, identifying or having their strengths identified out loud is a first-time experience and can be quite profound.

Your CIL may already have strengths-based items on the interview forms. If not, consider creating your own checklist to guide questioning. Better yet, work with colleagues to incorporate strengths-based items into your center’s forms.

Wrapping Up the Initial Interview

Whether or not the initial intake interview is completed in one session or over multiple appointments, conclude the interview or interview session in an effective way. Consider doing the following at the conclusion of each interview:

1. Let the consumer know that the end of the appointment is approaching by briefly summarizing the main areas discussed, and asking if the consumer has anything else to bring up or add before the end of the appointment.
2. Ask if an additional appointment to continue the initial interview would be helpful to the consumer.
3. Review the decisions that were made and discuss what the individual and staff will do next. Make sure that both parties have a clear understanding of who will do what and by when. IL Specialists play a critical role in ensuring that the consumer's independent living planning is thorough. Adequately document your role in assisting the consumer. This will lead to more accountability and a greater chance of consumer success.
4. Provide the consumer with any additional needed information and copies of interview notes and forms signed by the consumer.
5. Set up the next meeting or additional follow-up, whether that is to occur in person, by phone, e-mail, etc.
6. Thank the consumer for his or her time. Leave on an optimistic note, and provide encouragement by reiterating consumer strengths or positive traits.

Additional Resources

To learn more about some of the topics introduced in this chapter, such as Active Listening and Strengths-Based Approach, visit some of the following websites:

Active Listening Links:

“Active Listening: Hear What People are Really Saying”
<http://www.mindtools.com/CommSkill/ActiveListening.htm>

“Ten Tips to Effective and Active Listening”
<http://powertochange.com/students/people/listen/>

Strengths-Based Approach:

Strengths-Based Social Work Practice:
http://en.wikibooks.org/wiki/Strengths-Based_Social_Work_Practice

Chapter 4. Goal Setting with Consumers

Chapter Objectives

In this chapter you will learn:

1. The importance of helping consumers consider, identify, and reach their independent living and community integration goals in significant life areas.
2. What goals are and how to write them.
3. That goals need to be developed at the consumer's direction with the support of the IL Specialist.
4. The significance of goals in meeting federal requirements for the Consumer Information File and the reporting requirements of the annual Program Performance Report, completed by all federally funded centers for independent living.
5. The importance of planning activities and utilizing core services to achieve goals—determining what needs to be done, when it needs to be done, and who is responsible.

Introduction

The IL planning process is centered on consumer goals.⁶ The term “IL planning process” is used in this chapter to refer to the process of identifying the needs of eligible consumers, and jointly defining the goals required to address those needs. The IL planning process occurs both with consumers who choose to develop an Independent Living Plan (ILP), as well as those who choose not to and instead opt to sign a waiver.

IL services will be a means or avenue used to achieve the goal, not the goal itself. The goals identified by the consumer determine which specific CIL services will be provided to increase consumer independence. Consumers should be encouraged to think beyond a service to the ultimate goal to be achieved or significant life area to be affected. Consumers increase their independence, leadership, empowerment, and advocacy through achieved goals. Developing goals jointly with consumers is a critical step in ensuring that their needs are addressed and that requested services take place in a timely manner. Reported completed goals also demonstrate to funders that the services provided by CILs are making a difference in the lives of individuals with disabilities and in their communities.

Encourage consumers to take the lead in developing goals, while providing them with the necessary tools and information to make informed choices. Making those choices and decisions will not only empower consumers, but will also ensure that their needs are considered and addressed. In addition, if consumers are “calling the shots,” they will

⁶ Rehabilitation Act, as amended. Sec. 725 Standards and Assurances for Centers for Independent Living.

experience “ownership” of the IL planning process and will be more motivated to complete needed activities.

Goals should be clearly stated in the Consumer Information File (CIF), whether the consumer develops an ILP or chooses a waiver. If an ILP is developed, the IL Specialist and the consumer must sign it. If the plan is waived, the waiver must be signed by the consumer and IL Specialist. Whether there is a plan or a waiver, written goals are still required.

It is the IL Specialist’s responsibility to support consumers in identifying and reaching their ultimate IL and community integration goals, rather than simply providing them with services. Although responding to the request for a service may seem appropriate (and straightforward), a specific service does not usually address broader significant life areas and is only a limited part of what consumers need to increase their independence and reach their goals.

Goals should relate to the significant life areas outlined in the PPR wherever possible. These are:

- Self-advocacy and self-empowerment
- Communication
- Mobility and transportation
- Community-based living
- Educational
- Vocational
- Self-care
- Information access and technology
- Personal resource management
- Relocation from a nursing home or institution to community-based living
- Transition of youth from secondary education to post-secondary life
- Community and social participation

The PPR also mentions:

- Transportation
- Health care services
- Assistive technology

Other life areas that some CILs consider with consumers include:

- Attendant care
- Legal issues
- Nutrition
- Housing

Briefly reviewing each of these areas with consumers will improve the likelihood of identifying and addressing broader and more meaningful goals that result in increased independence, leadership, empowerment, self-esteem, self-worth, and productivity. It is important to talk with consumers about a range of possible goals that they are interested in, but it is also important to assist consumers in prioritizing what they consider to be the most immediately important goal.

What Are Goals?

Goals identify the consumer's specific desires. All of us are far more likely to attain what we want by identifying and setting goals, thinking through a logical plan to achieve them, and then taking action in a timely manner.

Requesting a specific service is not the same as identifying a goal in a significant life area. Goals are what we want to accomplish (ends), and the services are the means to achieving these goals or ends. Consumers will often request a specific service (such as getting a ramp to their home). Wherever possible, the IL Specialist should encourage the consumer to think beyond the ramp to how it may lead to an improved quality of life in a significant life area. Additional questions may be posed, such as:

- "Why is the ramp important?"
- "If you had a ramp, what would you be able to do with your life that you can't do now?"
- "Will it help you stay in your home and community, get a job, or go to school?"
- "If staying in your home and community (significant life area—community-based living) is the goal, what are some other needs that you may have?"

While identifying the goal(s) is an important step, it is also very useful to jointly develop a road map by specifying which practical actions, logical steps, and core services are necessary to fulfill the stated goal(s). Any potential barriers or problems should be identified and discussed, along with strategies to resolve them. Developing realistic and well-thought-out actions at the consumer's direction will help ensure that his/her goals will be accomplished.

Identifying Goals

Through each interaction with consumers, it is essential to keep the power of consumer control in mind. Work diligently to ensure that consumers take the lead when discussing their hopes, dreams, and goals for the future. The IL planning process must be truly meaningful to the individual. Consumers must see this process as their own plan for the future, not the CIL staff's plan.

The IL Specialist may need to encourage consumers to think about goals that address significant life areas, are manageable, and are realistic to accomplish. Requesting a particular service addresses an immediate problem, but does not ensure that significant life areas are considered.

Your role is to help individuals create achievable goals that fit within the framework of community resources and supports as well as within the boundaries of ethical, legal, and safety standards. This can be a difficult balance to strike, but these issues should be kept in mind and openly discussed with individual consumers as needed.

For instance, there is an individual who wants to train to participate in the Paralympics. The IL Specialist could, at a minimum, refer the consumer to a community or state group that has appropriate training programs, link them with others in the community with similar goals, and follow up on how successful the referrals and contacts were. Or perhaps the consumer is really looking for recreational and/or competitive sporting opportunities. Unless the IL Specialist listens carefully and asks good questions, an opportunity to develop goals and activities may be missed.

It is important not to limit consumer goals. It might be easy to encourage individuals to set goals that require services in the areas with which you are familiar, such as home modification or assistive technology, but an individual's needs and desires may go well beyond your familiarity. It's not necessary to be an expert in all areas, or even offer the services that consumers need to achieve their goal(s). Your role is to help the individual plan and complete the steps necessary to accomplish his or her goal(s).

Consumers often have numerous goals that they want to accomplish. After carefully listening, ask the consumer to select one or two goals to begin working on. Multiple goals can be overwhelming, and can also interfere with the consumer accomplishing specific steps on any of the goals. If there is too much to do, nothing may get done. The other goals can still be worked on after the first ones are accomplished.

Writing Goals

Consumers identify their own goals and are responsible for their successful completion. The IL Specialist supports and assists, but does not take the lead. In order to emphasize consumer goal ownership, many CILs find it useful to ask consumers to write their goals on the Independent Living Plan or on a goal form if they have waived the ILP. If a consumer has difficulty writing, the IL Specialist can assist, but use the consumer's own words. Wherever possible, the goals should be expressed in terms of the significant life areas outlined in the PPR.

Some centers recommend that consumers write their goals in the first person. Starting the goal with “I” reinforces who is in charge and whose goal it is. The goal should also be stated in the present tense and in a positive way. “I would like to move out of my parents’ house” is less positive and empowering than “I will move into my own apartment.” The IL Specialist may need to assist consumers in framing their goals to be positive. Positive statements set the tone and lead to positive results.

Goals should focus on what the consumer will do, not what someone else should do. “My boss needs to give me a raise” describes what someone else should do. A goal that states, “I will be a better employee by being on time and finishing all my work,” focuses on what the consumer will do.

Goals should be specific. A goal that states, “I will find an apartment,” describes what the consumer wants in a broad way. Stating, “I will find a one-bedroom accessible apartment in a secure building, close to the bus line on the northeast side of the city, for \$250-\$300 per month,” is much clearer and easily leads to the action steps. When the goal is written in a detailed way, it is also easier to measure and report on whether the goal was achieved. Goals that are too narrow, too broad, and/or not clearly documented may result in not being counted as successes.

Developing reasonable goals, and then clearly documenting and reporting them will result in a more accurate assessment of the CIL’s performance.

- Do not include the development of an ILP as the first goal since this is only an action step toward reaching goals.
- Goals should be simple with a specific purpose. Big multi-part goals can be separated into two or three smaller goals.
- Make sure that goals don’t conflict with each other.
- Goals should be obtainable.
- Consumers should want and believe in their goals, not just list what sounds good.
- Consumers should be able to identify why they want to accomplish each goal.
- Goals should be outcome-based, measurable, realistic, and time-framed.

Developing a Road Map to Achieve Goals

Once the goals are identified, assist the consumer to develop action steps, including the IL services to be provided by the CIL, community activities facilitated by the CIL and/or actions taken by consumers. CIL services should reflect one or more of the IL core services (information and referral, IL skills training, peer counseling, individual and systems advocacy, and “transition”) and other IL services provided by the CIL, as appropriate. Again, the quality and quantity of results that are achieved will depend on the IL services and specific actions that are planned and completed.

Try to brainstorm at least five (5) to ten (10) action steps and IL services to achieve the goal. For each action step, discuss possible barriers and solutions. It is critical to identify barriers as soon as possible, so the consumer (with the support of the IL Specialist) can also identify solutions or actions steps that will work around, minimize, or eliminate the barrier(s).

Remember, if a goal has too many action steps and IL services (some believe 10 or more are too many) or if the steps are too big, then it should probably be broken down into two goals. Goals that are too large (and consequently have 10 or more action steps) are overwhelming and it is easy for the consumer to become discouraged.

In discussing the action steps, ask the consumer which action steps and IL services he or she prefers and feels can be accomplished. Ownership of the action steps is critical to success and will increase the likelihood that the consumer will take action.

As steps are discussed and written, use the same guidelines as writing goals:

- The consumer should write the action steps (with assistance as needed).
- Use first person language—"I will...."
- Use positive, present tense language.

When an action step requires the participation of the IL Specialist, it may be written as, "I will ask my IL Specialist to assist me in formatting my résumé properly." This keeps the consumer in the "driver's seat" but also acknowledges the assistance of the IL Specialist.

As the consumer determines the action steps, the IL Specialist should provide, as needed, relevant information so that the consumer can make informed choices. The consumer should be able to explain how he or she identifies "success."

Examples of Goals and Action Steps

The following is an example of a goal in a Significant Life Area (per the PPR), and action steps. For each action step, some possible strategies are listed. This is an example of how consumers may choose different strategies to achieve their goals—that is, "how" they will accomplish each step.

Significant Life Area: Vocational

Goal: I want to become employed within the next three months so I can have my own money.

Action Steps:

1. I will identify my interests by discussing them with my IL Specialist and making a list.
2. I will identify my marketable skills by:
 - Thinking about which jobs I have had in the past and making a list to discuss with my IL Specialist.
 - Contacting the Vocational Rehabilitation agency to determine if a VR counselor can assist me.
3. I will identify local businesses that match my interests and skills (by checking the newspaper, Internet, word of mouth, bulletin boards, and making phone inquiries).
4. I will increase my ability to complete job applications by updating my résumé and:
 - Filling out 2 or 3 applications with my IL Specialist until I can do it by myself.
 - Keeping a copy of one of the applications so that I always have my information available for me to use.
5. I will increase my interview skills by asking my IL Specialist to assist me in role-playing. This will help me learn when it is appropriate for me to discuss my disability and any accommodations that I might need.
6. I will begin applying for positions that I am interested in, following application directions from each employer.

Setting Timelines

Goals should include timelines for completion to encourage progress, as well as to document that progress. Documenting progress may give consumers a sense of accomplishment and help them realize the headway they are making. Good documentation supports the CIL by reporting all consumer achievements and the CIL services that were provided. The IL Plan must indicate the established goals, the services to be provided, and a timeline for achieving the IL goals as well as for the provision of each IL service to be provided in support of the goals.

Timelines should be reasonable, realistic, and specific. For example, stating that “the consumer will contact a person or agency by a specific date” or “the first week of next month” is better than “the consumer will contact a person or agency sometime in the next several months.” Without deadlines it is easy to put things off, and consumers might not make the progress that they want. Everyone is more likely to start working

when dates are set to get certain steps done. Consumers are more likely to attain their goals if each step is planned with realistic timelines.

Goals extending beyond six months may need to be broken down into smaller goals that can be accomplished more readily. It is important for consumers to see that progress is being made toward achieving their goals. Many centers find it helpful for consumers to develop realistic goals that can be accomplished in 3-4 months rather than year-long goals. A consumer may have a goal of transitioning out of a nursing home and into the community. Depending upon the individual's situation, this broad goal could encompass several smaller, more manageable goals. Before the consumer transitions into the community, he or she may need to address the areas of transportation, housing, personal care, benefits, Social Security, and the purchase of household items or assistive technology.

Identifying Who Is Responsible

It should be clear who is responsible for each activity related to the goals. Since it is the consumer's goal, he or she is also responsible for accomplishing the action steps. If this is not specified, it is easy for the consumer to assume that CIL staff will make needed phone calls or complete other activities. Writing down who is responsible for completing each activity with timelines makes it more likely that the activities will be completed in a timely manner.

Peer counseling and relevant community services should also be considered when identifying any additional resources needed to achieve goals. Identify the person who will provide the service (if possible), the service that will be provided, and a deadline.

One of the challenges in establishing goals is the fact that the consumer may not be able to accomplish the goal at this time. The IL Specialist needs to keep in mind that the consumer has the "right to fail" just as we all do. The consumer may find barriers to success when the action steps needed to achieve the goal are started.

At this point the consumer may want to decide whether or not to change or modify the goal or to identify different strategies to be used. It's okay to find out by trying. Likewise, IL Specialists may think that the consumer cannot possibly be successful with goals only to find out that the goals were indeed achievable! The bottom line is that consumer control and choice are critical to achieving meaningful goals.

Example Independent Living Plan

This IL Plan sample shows the goal, action steps, timelines, and person responsible. For more IL Plan and waiver examples, see <http://www.ilru.org/resources-consumer-service-records>.

Independent Living Plan			
Consumer: Arlo Guthrie		IL Plan: Accepted Waived Dropped	
IL Specialist: Roy Rogers			
Goal Category: Vocational			
Goal Note: I want to become employed as a waiter within the next three months so I can have my own money.			
Outcome Date: _____			
Consumer Is the Person Responsible for ALL Action Steps	Start Date	Anticipated Date of Completion	Completion Date
Step 1: I will meet with my IL Specialist to develop/update my résumé. I will bring a list of my former positions along with dates of employment. I will follow up with my IL Specialist to make sure he made copies of my new resume.	1/5/20	1/19/20	1/19/20
Step 2: I will complete a sample application, using the information from my résumé, with my IL Specialist.	1/19/20	1/19/20	1/19/20
Step 3: I will look for job openings by asking my friends and family about openings they may know about, checking the newspaper, and searching the Internet. I will apply for openings that	1/5/20	3/30/20	3/30/20

interest me and I will send my résumé to places where I would like to work.			
Step 4: I will begin to apply for positions that interest me, following the directions from the employer on how to apply.	2/2/20	3/30/20	3/30/20

_____ Consumer Signature
 _____ Date

Evaluating the Planning Process

The CIL may find it useful to provide a satisfaction evaluation to the consumer when the goals are established in order to measure their satisfaction with that portion of the process. Each CIL can decide what form of feedback works in its locale. Whatever approach you use can provide valuable insight about how well your services are being received. It can also help inform next steps for appropriately assisting the consumer. Remember, if consumers are not given the opportunity to give feedback on the CIL's services they received, the process cannot be considered fully consumer controlled.

Solution-Focused Approach

In the process of supporting consumers in identifying goals and the action steps to achieve them, it is important to use a solution-focused approach. Much like the strengths-based perspective (see Chapter 3—Interviewing), a solution-focused perspective is about framing or describing a situation from a positive perspective versus a negative perspective.

Using a solution-focused perspective can help consumers move quickly and effectively to a discussion about what can be done to improve their current situation versus getting bogged down in all the things that aren't working well and whose fault that might be. An IL Specialist using a solution-focused perspective could begin by discussing the steps that the individual could take to begin working toward solutions that would address barriers that are preventing independence.

A solution-focused perspective is based on the following main ideas:

- Focus on what consumers are already doing well that might lead to concrete solutions.
- Focus more on exploring future goals, current resources, strengths, and future hopes than discussing the past and current causes of the problems and barriers.

Periodic Follow-Up

The Independent Living Plan services should be reviewed periodically and monitored at specific intervals. An IL Plan must be reviewed as often as necessary, but at least on an annual basis.

The annual review should determine whether independent living services should be continued, modified or discontinued, or whether the individual should be referred to any other program of assistance.

Meeting with the consumer on an ongoing basis is an effective way to assist him or her to move forward with the goal. The frequency of meetings will depend on CIL practices and individual consumer needs. Meeting at least twice per month (one-on-one meetings, phone calls, e-mail, or remote technology such as Zoom or Skype) is recommended by many to support the consumer in actively addressing goal(s).

Completing Reviews or Evaluations

Conducting reviews or evaluations will make it possible to consistently improve services. After the completion of each goal, the IL Specialist should ask the consumer to think about what was accomplished, what was not accomplished, and if things went according to plan. Possible questions may include:

- Would you do anything differently next time?
- Should another organization or peer mentor have been involved?
- Would another solution have worked better?
- What can be done better or differently next time if another consumer identifies a similar goal and/or objective?

It would be useful to ask all consumers the same questions to recap what each person learned and if there are any areas for improvement.

At the end of this process, after all the goals are completed, a consumer satisfaction survey should be given or sent to the consumer to determine their satisfaction with services as a whole.

Documentation and Reporting Requirements

CILs are responsible for documenting and accurately reporting their IL goal-related activities, including:

- Goals set and met
- Services provided
- Facilitation of goal development and achievement
- ILPs and ILP waivers

- CIF periodic reviews
- Coordination of services with other agencies

These and other activities must be:

- Documented in the CIF (including the Independent Living Plan, waiver forms, intake forms, goal and service worksheets, file notes, and narratives);
- Reported in the PPR⁷ accurately and without duplication, in accordance with the PPR Instructions and Key Guidance for Ensuring PPR Report Compliance and Data Integrity; and
- Made available to the Administration for Community Living (ACL), the federal agency with oversight authority for the Independent Living Program, or the Designated State Entity when appropriate.

CILs' compliance with these and other program requirements related to the Standards and Assurances in section 725(b) and (c) of the Rehabilitation Act are subject to ACL review and verification through on-site reviews and/or other monitoring activities. ACL requires that CILs adopt written policies and procedures to ensure that consumers are well served, goals and services are adequately documented, and program activities are accurately reported in the PPR. Center policies and procedures should include specific action steps, quality control practices, and assigned responsibilities.

Summary and Conclusion

Goals are the heart of IL services. Collaboratively developing meaningful and realistic goals with consumers that address all their needs and specify the steps that will be taken—along with timelines and responsible parties—will significantly increase their independence, result in more accurate reporting of services, and fulfill the center's core mission.

⁷ 45 CFR 1329.6 Reporting.

Chapter 5. Consumer Information Files

Chapter Objectives

In this chapter you will learn:

1. What a Consumer Information File (CIF) is.
2. What an Independent Living Plan (ILP) is.
3. The fundamental federal requirements for record keeping and reporting.
4. The importance of CIFs in meeting the reporting requirements for the annual federal PPR of services and activities that all CILs must complete.
5. Useful practices for gathering consumer information, developing ILPs, and maintaining complete and accurate records.

Complete and Accurate CIFs

Accurate and timely record keeping is critical to a well-functioning CIL. Some CILs designate a staff member (often a program manager) to conduct quality control by regularly reviewing CIFs to ensure they are complete and accurate. Some CILs review all records; others review a random sample. ACL requires that each record is reviewed at least annually and that a decision be made whether to continue or discontinue services. Regardless of the approach your CIL chooses to take, ACL requires that your CIL have and follow written policies and procedures for managing CIFs.

Fostering High Quality Services

Good records foster an organized approach to providing and documenting services. A structured process supported with effective forms and well-maintained records ensures the consumer has complete information to make sound decisions about his or her future. The consumer will have a plan that will allow him or her to track and follow results. Up-to-date records promote continuity of services, even with staff absences and staff changes. The consumer will learn planning skills by participating in goal setting that will be useful in many areas of life.

Supporting Systems Advocacy, Program Planning, and Reporting

Reports drawn from CIFs help your CIL:

- Track problems encountered by multiple consumers and provide documentation for policy change, legislative advocacy, and systems change actions.
- Collect data that facilitates long-term planning and resource allocation.
- Secure data for funding requests and grant proposals.

- Meet requirements of CIL Standards and Assurances.
- Provide accurate data for federally required reports, including the annual PPR (See Table 1.1), and for on-site compliance reviews and audits.
- Demonstrate satisfactory progress to qualify for CIL continuation award funding.
- Increase accountability at the state and federal level.

Any information in the CIFs and/or reported on the PPR is subject to verification by ACL through on-site and/or other monitoring activities.

Information and Referral to Intake

For many individuals with disabilities, an initial contact with a request for information may be the beginning of a longer-term relationship with the CIL. Information and referral (I&R) inquiries may lead to an individual opening a CIF, but I&R may be provided without the requesting individuals having a CIF. The requesting individual does not have to have a disability.

When a request for information is received:

- Provide complete information in response to the request or make a referral to a useful resource.
- Record the contact. Show the time and date of the contact and the information requested. Some CILs also record the name of the caller and contact information so that follow-up calls may be made if additional information or a new resource should become available. Follow-up calls can also be used to verify whether the information provided helped the caller obtain access to previously unavailable transportation, health care, and assistive technology, as required in the PPR.

If the request requires more than a straightforward referral or the individual expresses multiple concerns:

- Ask if the individual would like an appointment with an IL Specialist who could spend more time to discuss needs in greater depth. If the individual is interested in doing so, schedule the appointment.
- Secure basic contact information and document the needs that were identified by the individual. This will enable the IL Specialist to concentrate on forming a relationship and determining needs without requesting information that has already been obtained.

Determining Eligibility for Services

At the first meeting with the individual, determine whether he or she is eligible for services through the CIL. An individual is eligible when:

- The individual has a significant disability which means an individual with a severe physical or mental impairment whose ability to function independently in the family or community or whose ability to obtain, maintain, or advance in employment is substantially limited and for whom the delivery of independent living services will improve the ability to function, continue functioning, or move toward functioning independently in the family or community or to continue in employment, respectively.⁸
- The individual with a significant disability requests services.

Eligibility must not be limited to individuals with a certain type of disability or circumstance.⁹ The eligibility determination must be documented in the Consumer Information File. The eligibility determination may be maintained on the intake form or as a separate eligibility determination form, and typically the person requesting services self-discloses a significant disability. The documentation must be dated and signed by an appropriate IL Specialist.

Ineligibility for Services

If an applicant for IL services is determined not to be an individual with a significant disability, the CIL must provide documentation of the ineligibility determination and be signed by the appropriate staff member. It is also a recommended practice for the CIL to notify the individual *in writing* of this determination and inform the individual, or the individual's representative, of his or her right to appeal the action taken.

The CIL *must* provide an explanation of the availability and purpose of the Client Assistance Program, including the information on how to contact the CAP.

If the person requests services that the CIL does not provide, an appropriate referral should be made. Some centers document the referral in the applicant's file, including information on where needed assistance is available, how it may be accessed, and any specific eligibility criteria, cost, or restrictions.

Gathering Essential Information

CIF Intake Form

Much of the basic information that will help in providing high quality consumer services is best gathered during an initial intake interview. CILs are encouraged to develop a standard set of forms to be used by all staff. It may be useful to develop your forms around the information needed in your PPR.

Before starting to fill out the forms and gather needed information, make sure that the application process and the reasons for asking personal questions are fully explained to the consumer. Recording information about the consumer on a well-organized initial

⁸ 45 CFR 1329.4 Definitions.

⁹ Rehabilitation Act, as amended, Sec. 725 Standards and Assurances for Centers for Independent Living.

interview or intake form will help with maintaining and locating important information about the consumer. It is likely that this intake form will be referred to often during the service coordination process.

Standard Information to Include in Each Consumer Information File¹⁰

Standard information in each CIF should include:

1. Basic consumer information
2. Full name
3. Mailing address, county of residence*, e-mail or telephone numbers.
4. Age*
5. Gender*
6. Race/ethnicity*
7. Type of disability.*¹¹ A consumer may describe several disabilities or conditions. If there are two or more disabilities/conditions that impact independent living, list each one.
8. Documentation of eligibility/ineligibility* (signed and dated by the IL Specialist).
9. A written ILP (jointly developed and signed by the appropriate CIL staff member and the consumer or legal representative), or written waiver from the consumer stating that an ILP is unnecessary.
10. IL goals *established* with the consumer written in an ILP or separately in the CIF if the consumer has waived the plan.*
11. IL goals *achieved* by the consumer documented in an ILP or separately if the consumer has waived the plan.*
12. Documentation of the CIL's facilitation of goal development, pursuit, or achievement.
13. Services requested by, and the services provided to, or arranged for, the consumer.* When an eligible individual requests services from a CIL, other than the simple provision of information or making a referral, a CIF is created.
14. A service narrative record with complete yet succinct notes documenting each in-person contact, telephone call, or other communication that describes actions taken, results, and other pertinent details relative to the development and achievement of IL goals by the consumer. (Recommended practice).

¹⁰ See ACL's "Consumer Information File Checklist" which is part of their Compliance and Outcome Monitoring Protocol (COMP) tools available at <https://acl.gov/programs/il-comp>.

¹¹ *Identifies items required for the PPR.

15. A notation of ILP review (at least annually) to determine whether services should be continued, modified, or discontinued and/or the individual referred to another program, including VR, as appropriate.
16. Release of information form signed by the consumer or authorized representative (as required/needed).
17. Notification about consumer opportunity to express satisfaction or dissatisfaction.
18. Notification about the Client Assistance Program (CAP), with availability of accessible formats.
19. Notification about consumer's ability to appeal CIL's decisions.
20. Notification about alternative format and communication modes availability.
21. Documentation showing notification to the consumer of their right to develop, or waive the development, of an ILP (Recommended practice).
22. Notification about closure of the CIF (Recommended practice).

The CIF may be maintained either electronically or in written form.

Information That May Be Documented in the Consumer Information File

A Participant Rights and Responsibilities Statement may be included in the CIF, including a statement signed by the applicant documenting that he or she has received a written description of his or her rights and responsibilities. The Statement may include information detailing the ways to give feedback to the CIL about the service experience (consumer satisfaction). Copies of the form or forms may be retained in the CIF.

One of the rights the consumer has is the right to confidentiality. The CIL must have policies and procedures that safeguard the confidentiality of all personal information, including photographs, publicity releases, and lists of names that comply with federal requirements.

A release of information form must be completed and signed by the consumer (or his/her representative) prior to CIL staff accessing specific information that will assist them in providing more effective services to the individual. Obtaining blanket releases that give permission for CIL staff to access information from multiple sources over an extended period of time is not recommended. It is recommended that you have a separate Release of Information form signed for each organization from which information will be requested or to which information will be provided. The information should be essential to the consumer's goals. Many CILs complete each release form at the time that the information is needed. Media releases signed by the consumer should be found in any case where the CIL utilizes quotes, photographs or other information about the consumer in media the CIL provides to others.

HIPAA Rights Documentation

If your CIL provides health-related services, documentation may need to be included that the consumer was informed about his/her rights under the Health Insurance Portability and Accountability Act (HIPAA). Check on HIPAA requirements through the programs associated with health-related services that the CIL provides.

Documentation of Receipt of Client Assistance Program (CAP) Information

All CILs must notify each individual seeking or receiving their services about the availability of the Client Assistance Program, the purposes of the services provided by the CAP, and how to contact the CAP.¹² The CAP is an agency funded specifically to advise and inform applicants and individuals eligible for services and benefits available under the Rehabilitation Act, as amended. It may provide advocacy in pursuing legal, administrative, or other appropriate remedies to ensure the protection of the rights of such individuals.¹³ The CIL must include documentation of this notification as part of the CIF.

Independent Living Plan (ILP)

After the individual has been determined eligible, the IL Specialist should offer the opportunity to develop an ILP or a consumer may choose to waive the right to develop an ILP. If the right to develop an ILP is knowingly and voluntarily waived, the consumer must sign a waiver stating that an ILP is unnecessary. The ILP must be signed by the consumer.

As is true for all materials provided to or used with applicants and consumers, the plan or waiver must be provided in an accessible format to the individual with a significant disability, or—if consistent with State Law and if what the individual chooses—to his/her guardian, parent, or other legally authorized representative.

An ILP assists both the consumer and the IL staff to be clear about what the consumer's goals are and which steps are necessary to reach them. A written plan is an excellent way to help the individual:

- set a course of action, including anticipated duration of the service program and each component service,
- stay focused, and
- review and document progress.

Plans are not burdensome paperwork if they are used—not just filed!

¹² Rehabilitation Act, as amended, Sec. 725 Standards and Assurances for Centers for Independent Living.

¹³ Rehabilitation Act, as amended, Sec. 112.

Developing Goals

Goals are a critical and required part of the ILP and can be identified by spending time with the consumer to explore his or her needs. Chapter 4 provides an in-depth look at the goal-setting process.

Document goals and action steps for any consumers who have independent living goals they want to achieve, even for those who do not wish to develop a formal plan (but who have signed a waiver).

Provide a copy of the ILP in an accessible format to the consumer when it is created or changed.

Documenting Progress

Good documentation ensures continuity and consistency of services, regardless of which CIL staff member provides services. This is especially important if there are staff changes or when a staff member is on leave or away from the center for other reasons. Document any progress when each contact is made. Record brief notes (narrative entries) in the CIF for each contact. Examine all forms and information in the CIF to ensure information is still accurate when meeting with the consumer to review the ILP. Then, make appropriate changes and updates.

The ILP should be reviewed as often as necessary, but annual reviews are required to see if services should be continued, modified, or discontinued, or whether the consumer should be referred to any other program. Many CILs review plans at different intervals: monthly, quarterly, or semiannually to maintain both engagement with the consumer and ensure that the ILP is moving forward.

One way that many CILs have found to stay current with the ILP is to have the consumer and the designated IL Specialist sign and date changes, updates, and reviews of the CIF and ILP.

In assessing the quality of CIF narratives, CILs should evaluate whether the narratives demonstrate the IL Specialists' role in facilitating the development and achievement of the consumer's IL goals.

Closing the CIF

The CIF represents an active partnership between the consumer and the CIL. The CIF should not remain open if joint activities are not occurring. The PPR asks for the number of CIFs that have been closed out of the active files during the reporting year because the consumer:

1. Has achieved goals and does not want to set new goals at the time.
2. Asks to discontinue services.
3. Relocates with no forwarding contact information.
4. Is deceased.

5. For other reasons than those listed above.¹⁴

Remember, the CIL may not impose any duration limits on IL services. Sometimes a consumer may become discouraged and decide to stop working on goals. If this occurs, the IL Specialist can encourage the consumer to continue by suggesting other approaches or even a change in goals. If the consumer still does not want to continue, the CIF should be closed. Closing the CIF includes notifying the consumer in writing of the action taken, the availability of CAP services, and referrals to other agencies as appropriate.

Also remember that closing the CIF does not mean ending the relationship with the consumer. Flexibility and availability have been hallmarks of centers over decades. With the simple process centers use to open and reopen CIFs, they continue to be highly responsive to consumer needs. A CIL can open a new CIF for an individual if the previous CIF has been closed for a period of time. CIFs may be reopened if the individual's circumstances have changed and/or an additional service is requested.

Documentation of Closure

In closing a CIF, recommended practices are as follows:

1. Notify the consumer in writing that his or her CIF will be closed, but can be reopened if the consumer requests that it be reopened within 10 days.
2. Place a signed and dated copy of the closure letter in the CIF.
3. Move the file to an inactive status. In many CILs, this means physically moving the file to a separate file cabinet, electronic file, or area of the CIL office.

Recording Information from the CIF in an Information System

Many CILs record data in an information system so that information about services requested or provided and goals set or achieved can be summarized for planning and reports to funders. These systems may be as simple as an electronic spreadsheet or as sophisticated as a customized system developed especially for a single CIL. A few CILs record information using card files or paper registers.

When using an electronic system, it is still necessary to obtain consumer and IL Specialist signatures and provide the consumer with a copy of the ILP.

Although these systems operate differently and may use different forms for data collection, in most cases the CIL staff member will record the following in the system:

- Information from the initial interview form, for example, name, address, age, gender, disability type

¹⁴ Other reasons may include things such as the consumer does not return calls, attend meetings, or demonstrate interest in working on the goals in the ILP; or there has been no activity for a significant period of time, such as 90 days.

- Dates of application, opening a CIF, and closing a CIF
- Whether the person chose to develop an ILP or waived the ILP
- Goals set and goals achieved
- Information about each contact with the consumer
- Services requested and provided

Regardless of the system used, it is crucial that data be entered accurately, regularly, and frequently. Backlogs in entering data lead to errors and associated problems in reporting. To ensure consistency and accuracy in maintaining CIFs, the CIL should have written CIF management policies and procedures, and designate responsibility for overseeing the maintenance of CIFs. One useful practice would be to develop a quality assurance process for periodically reviewing a sample of CIFs maintained by each IL staff. The results of the review could be used to identify training needs of the IL staff and also used in staff performance evaluations.

Accessibility of Materials and Communications

Communication is at the heart of an effective CIL and supports consumer participation and empowerment from basic information and referral functions, through intake, to the Consumer Information File and the Independent Living Plan. Information and services must be provided in accessible formats to all individuals who request this type of assistance from the CIL. In addition, the CIL should make available all of its written policies, materials, and IL services in alternate formats, as appropriate, (e.g., Braille, large print, audio tape, electronic). Communication includes oral communication, written materials, and materials for consumers whose primary language is not English.

Access for Those Whose Primary Language Is Not English

Providing an interpreter for an applicant or consumer who does not speak English or with limited language skills will help the individual to fully understand all aspects of applying for and receiving services from your CIL. To the maximum extent feasible, the CIL must make available information and services in the native languages of individuals with significant disabilities whose English proficiency is limited and who apply for or receive IL services. CIL staff must also receive training on how to serve unserved and underserved populations, including minority groups and urban and rural populations.

Accessible and Alternate Formats

Regardless of the type of activity or service, all communication must be in a format or mode readily useable and accessible to those requesting or receiving services from the CIL, such as:

1. Sign language or oral interpreters for interviews and meetings.

2. Videophone, TTD/TTY, or relay services for phone communication.
3. Alternate formats for those who do not read standard print, including large print, electronic files, Braille, audio tape, and material made available through accessible Web pages.

Readability of Materials

All materials provided to consumers should be written clearly in plain language. Use simple, direct language. Publishing experts recommend that material should be written at the 6th – 8th grade reading level. This reading level is generally used by newspapers. Most word processors have a feature that allows you to check the readability and reading level of a document.

ACL Monitoring and Review

It is important to remember that any information in the CIFs and/or reported on the PPR is subject to verification by ACL through on-site and/or other monitoring activities.¹⁵

CIL Evaluation Tool

ACL has developed a CIL evaluation tool that can be found at: <https://acl.gov/programs/il-comp>. The most relevant sections for CIFs and ILPs include Part I, Section 7: Independent Living Goals, Section 9: IL Core Services and Other IL Services, Section 12: PPR Accuracy and Documentation; and Part II, Section 4: Confidentiality. You should become acquainted with ACL's Compliance and Outcome Monitoring Protocol (COMP) and all the checklists/tools that are available on the webpage. Don't wait until your CIL is notified of an impending review. The more proactive you can be, the more you will be prepared for a review and the likelier you will avoid findings and the need for corrective actions.

Assessment of outcomes is guided by two principles: 1) The extent to which the grantee is achieving the purpose of the Act: The purpose of this title is to empower individuals with disabilities to maximize employment, economic self-sufficiency, independence, and inclusion and integration into society. 2) The extent to which the outcomes data collected and submitted by the grantee in the annual PPR can be validated.

List of Sample Forms

The IL-NET has a Web page with example forms from several CILs that can be used to develop and/or revise your CIF forms and ILPs. These forms are provided only as examples and have not been approved by ACL. Your CIL is responsible for ensuring that complete information is contained in CIFs. These forms consist of Single Purpose Forms and Checklists. The titles of all forms on the website are shown below. These

¹⁵ 45 CFR 1329.23 Compliance reviews.

forms can be viewed, downloaded, or printed from <http://www.ilru.org/resources-consumer-service-records>.

Single Purpose Forms

- CAP (Access to Independence, WI)
- CAP and Grievance Procedure (Walton Options for Independence, GA)
- Closure (Lifetime Independence for Everyone, Inc., TX)
- Consumer Application (Living Independently for Today and Tomorrow, MT)
- Consumer Goals (Wyoming Independent Living Rehabilitation, WY)
- Consumer Self-Assessment (Disability Partners, NC)
- Confidentiality Labels (Walton Options for Independence, GA)
- Consumer Agreement (Living Independently for Today and Tomorrow, MT)
- CSR¹⁶ Control Log (Walton Options for Independence, GA)
- CSR Legalities (Walton Options for Independence, GA)
- Goal Plan (Access to Independence, WI)
- IL Program Application (Tri-County Independent Living Center, UT)
- IL Plan (Tri-County Independent Living Center, UT)
- IL Plan (Wyoming Independent Living Rehabilitation, WY)
- IL Plan/Waiver and Goals (Walton Options for Independence, GA)
- Information and Photo Release (Walton Options for Independence, GA)
- Personal Information (Access to Independence, WI)
- Release of Information (Access to Independence, WI)
- Release of Information (Living Independently for Today and Tomorrow, MT)
- Rights and Appeals Process (Living Independently for Today and Tomorrow, MT)
- Service Commitment Form (Walton Options for Independence, GA)

¹⁶ CSR (Consumer Service Record) is the previous title for the Consumer Information File.

- Voter Registration Declaration Statement (Walton Options for Independence, GA)
- Waiver of IL Plan (Living Independently for Today and Tomorrow, MT)

Checklists

- Case Notes Checklist (Walton Options for Independence, GA)
- Closing Statement Checklist (Living Independently for Today and Tomorrow, MT)
- CSR Checklist (Walton Options for Independence, GA)
- CSR Folder Checklist (Walton Options for Independence, GA)
- Opening Statement Checklist (Living Independently for Today and Tomorrow, MT)

Program Performance Report (PPR)

Table 1.1 below shows how the information collected for the CIF corresponds to the information requested for the annual PPR.

Table 1.1 Comparison of CIF Information to Corresponding PPR Report Sections	
Information Gathered for CIF (either at the Center level or for individuals)	Corresponding Section of PPR Report
Total Number of CIFs in Closed File	Number of CIFs Closed by Sept. 29 of Reporting Year
Total Number of CIFs in Open File	Number of CIFs Open on Sept. 29 of Reporting Year
Total Number of Waivers in the Waiver File	Number of Consumers with Signed Waivers
Total Number of ILPs in ILP file	Number of Consumers with ILP
Basic Consumer Information Section of CIF	Number of Consumers by Age Category
Basic Consumer Information Section of CIF	Number of Consumers by Sex
Basic Consumer Information Section of CIF	Number of Consumers by Race and Ethnicity
Basic Consumer Information Section of CIF	Number of Consumers by Disability
Basic Consumer Information Section of CIF	Number of Consumers by County
Services and Goals Section of CIF	Types of Service Requested by what Number of Consumers
Services and Goals Section of CIF	Types of Service Received by what Number of Consumers
Services and Goals Section of CIF	Number of Consumers who Set Goals in Each Significant Life Area
Services and Goals Section of CIF	Number of Consumers who Achieved Goals in Each Significant Life Area
Services and Goals Section of CIF	Number of Consumers who have a Goal In Progress in Each Significant Life Area
Progress/Case Notes Section of CIF	Additional Information Concerning Individual Services or Achievements