

# **EXPANDING CIL CAPACITY THROUGH YOUTH- DRIVEN TRANSITION SERVICES**

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# **IL-NET**

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## Chapter One: Introduction, Purpose, and Background

### Policy Framework for Transition Services in CILs

Many consumer-directed centers for independent living (CILs) have been providing the service of assisting youth and young adults to transition from school and life with parents to post-secondary education, employment, and independent living for some time. On July 22, 2014, the Workforce Innovation and Opportunity Act (WIOA) was signed into law, bringing about a number of changes to the independent living program, adding new core services, including a “transition” component for youth.

The new core services are to:

- (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.

Final regulations went into effect November 28, 2016 and key elements are outlined in the Appendix.

For purposes of this manual, providing assistance to youth in transition is the primary focus. The manual contains tools and strategies the transition facilitator can use to conduct the fundamental tasks of an overall process with youth in transition.

### CILs Uniquely Qualified

Centers for independent living are unique in their abilities to facilitate the successful transition of young adults with disabilities. Even before assistance to youth in transition became a part of required core services, CILs saw the need to ensure that youth have the choices, advocacy, peer support, and independent living skills needed to transition to adult life and to leadership within the Independent Living movement. Because other entities are also mandated to assist youth, this is not always a simple task. Complex multi-agency planning is required as youth transition from high school to post-secondary choices, including education, employment, community participation, recreation, health care, leadership activities, independent community living, and ultimately to their future success and the achievement of their life goals.

Transition planning provides the blueprint for young adults to gain the skills and build the relationships needed to complete their goals and obtain independence. Centers play a key role in ensuring that transition services are youth-driven, coordinated, and all of the necessary components are included in the transition plan. Providing services that support transition helps young adults with disabilities put all of the needed pieces in place in order to run their own lives and accomplish their dreams. In the WIOA legislation, Congress added new IL core services that target specific populations. This includes a focus on youth who are out of school, as defined on page two. While transition services for this target population is now defined as part of core services, centers still serve all ages. Many centers providing youth services see a need to begin planning at a much younger age, often at age 14, which is when schools and vocational rehabilitation begin their youth services.

The goal of this guide is to enable your center to more effectively develop or enhance successful youth transition services. After following this guide you will 1) have information about the core service for youth in transition and other youth services the CIL may choose to provide; 2) describe promising practices and ideas for young adults with disabilities to be involved as an integral, fully included, part of centers; 3) understand how other centers have developed, supported, and strengthened youth services; 4) identify possible funding sources, including fees-for-service; and 5) develop a vision and ideas to either start or enhance services to youth in transition.

## Impact

When your center creates services that facilitate transition or improves services already in place, you provide opportunities for youth to improve options for themselves and for others. Some of the long-term community barriers can be alleviated. The work centers engage in will expand their capacity to make circumstances better for people with disabilities of all ages.

The core service identified in the Rehabilitation Act as amended by WIOA essentially means any independent living service provided to youth with significant disabilities<sup>1</sup> who are between the ages 14 and 24 (up to 25) **that assists them in the transition to post-secondary life.** The parameters identified in the law (post -secondary) focus on a specific population of youth. However, you are allowed to expand these parameters to include individuals who are still in school, as long as you can clearly identify those individuals who are considered youth who have left school. You can provide all core services to youth, but the required transition component has the intent to provide opportunities for post-secondary success. If your center doesn't yet serve youth that are in transition, you now need to develop them specifically for individuals transitioning to post-secondary life. You can serve other youth with significant disabilities if you wish, but must provide services to this group of young adults. A number of centers wrap their youth transition programs into their overall core services, as is now required.

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<sup>1</sup> "Significant disability" is the statutory language and has always been required for eligibility for IL services, and is self-disclosed. If your center has other income, you can broaden whom you serve.

Successful and effective services that support transition are integrated, not separate from the other services of the center. This guide will describe several of these successful services and programs.

There are some barriers to achieving smooth transition outcomes for youth with disabilities. Youth with disabilities are often not full participants in educational, employment, leadership, recreational or community activities. Often there are significant attitudinal and architectural barriers around both age and disability. Accommodations may not be optimal, due to funding and knowledge limitations. Transportation for people with disabilities continues to be an unresolved problem in many communities. Students do not always receive the highest quality education that leads to positive academic and independent living outcomes. Effective transition planning can identify these barriers along with possible solutions.

Many skills are necessary to build a successful adult life after youth leave school. Young adults with disabilities may lack needed independent living and employment skills and experiences to transition successfully from high school to post-secondary life. They need to master diverse independent living skills, but even more important to their transition, they need to apply self-advocacy and individual empowerment skills, not just to speak up, but also to gain the competency to know when discrimination and, sometimes, exploitation are taking place. Self-advocacy is also needed to become an active, contributing, and sometimes driving member of the planning that takes place in preparing for school, work, or other post-secondary options. Young adults may also need to know what services and resources are available to them.

## **Need for Services**

Comprehensive support systems, which provide practical advice, mentoring and guidance, are often nonexistent or only partially in place for youth with disabilities. Centers can fill this support gap for youth with disabilities to empower them to effectively address the above barriers and achieve successful transition outcomes. Of course transition is critically important for young adults with disabilities and their families, but it also significantly impacts their communities, the center, and the disability rights movement.

At the conclusion of this course, it is anticipated that each participating CIL will be ready to start or expand services to youth in transition, and to fully support young adults with disabilities as they transition to employment, post-secondary education, leadership, and independent living.



## Chapter Two: Why Provide Youth Transition Services?

Centers are now required to provide services to 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 (20 U. S. C. 1414(d)), and who have completed their secondary education or otherwise left school, to postsecondary life.

Centers, however, have always provided a range of core services (advocacy, independent living skills training, peer support, information & referral) to youth and young adults before the “transition” requirement of WIOA. Those services may or may not have been identified as supporting transition to postsecondary life. Each CIL has had its own approach to serving youth. The changes in the law are an additional factor in determining to what degree a CIL will serve youth. You might also think about the advantages of having emerging leaders with disabilities as active participants at your CIL. What an opportunity to prepare a new generation of leaders! Youth with disabilities have a fresh and different agenda. Young adults with disabilities bring energy, excitement, and enthusiasm, and can revitalize the center and its activities.

Youth with disabilities show the seasoned staff, board, and consumers that the advocacy work of centers made a difference. The fact that youth are mainstreamed for their education is due to the work of the disability rights movement. Advocacy efforts have improved accessibility and inclusion within communities, and the next generation is benefitting. Youth will benefit from learning the history of independent living.

Much has been achieved, but much still needs to be done. The need for continued advocacy and further inclusion will not lessen anytime soon. There will be enough work to go around, at least in the foreseeable future. We must prepare the next generation of leaders to carry on the effort for full inclusion in their future. The course of the disability rights movement is advanced even further when advocacy is done collaboratively with youth.

In addition to conducting advocacy, youth involved with the CIL are better connected to their community. Youth with disabilities can be isolated and not connected well with other people. One parent affiliated with a center stated that her child’s biggest challenge was not his disability; it was his loneliness. If CILs can take the edge off that loneliness and create a sense of community with young people with disabilities, then their transitions to adult life are more successful.

Young adults with disabilities are eager to have good peer relationships and make meaningful connections, but may not know how, or may not have frequent opportunities in their school life. Graduates from high school may not be connected to other people or involved in the community with their typical peers. Center transition services can connect youth to their peers and provide some sense of community. Through the CIL, youth can learn how to believe in themselves, navigate the systems that affect them, increase their social capital, pursue their dreams, and change their quality of life.

## Chapter Three: Creating Space for Youth in CILs

### As Staff, Interns, and Other Key Personnel

There are many ways that youth can become involved in a center, and it is important that centers consciously and consistently invite that participation. If you want your center to become the key locale for the disability rights community to gather, involve youth in every way that you can. When youth become involved with a center, it's critical that they see themselves as an integral and valued program participant, employee, or volunteer, so that they will be drawn into participating in their new role(s). It is common for CILs to have adults serving in the CIL coordination/program planning roles and youth only in unpaid or advisory board roles. It's a good idea to set up a youth advisory board, but try to also involve young adults with disabilities in the center as interns, staff, advocates, mentors, and (if they are legally adults) board members.

Offer leadership roles to youth who frequently attend activities. Help them move up to work groups, advisory groups, and steering committees; let them take the lead in more things. Help them organize their own activities and give them a budget. Put together a panel of youth experts.

Another idea that has been very successful is job shadowing. Let youth take a week to shadow a person that has a lot of responsibilities. This will enable them to start thinking through some of the decisions that leaders have to make. They will see things from a different point of view. Then you'll be able to help them move to the next step.

After youth are hired to work at the center, give them opportunities to head up projects and be in decision-making roles. Involving youth in centers in a meaningful way is an important responsibility. Young people with disabilities are often finding out who they are and what they want to do with the rest of their lives. They need to know that they can work, and internships, volunteer roles, or other work at the center provide them with that experience. What better place than a CIL for youth to start their careers? Encourage all of the office members to support and mentor the youth in the CIL office. While your center may have a youth specialist on staff, that is not the only person who should interact with youth with disabilities.

When youth with disabilities become involved with the CIL in primary roles, they enhance their knowledge, skills, and self-esteem. These youths also contribute their energy, enthusiasm, connections, and ideas to the successful functioning of the center. Future staff and leaders for the CIL can emerge through such opportunities. It is a win-win situation for everyone.

### As Program Participants

The opportunity to participate in activities and services with peers is a vital doorway for youth. This created space at the center and within center services may be where youth first have the opportunity to experience self-determination. It is often the first time they

are told that they are in the driver's seat of their lives. It is probably the first time they learn about the rich disability history and culture and experience disability pride. The center can help youth see that they are not less than anyone else and they are actually pretty cool, fun, and amazing people. Those are just some of the reasons why it is important to create that space for youth and to foster self-determination.

Youth will have more self-acceptance when they understand that they aren't alone in the way that they feel and the things they are going through. Often young adults do not have the chance to discuss their disabilities with their peers. They have been exposed to sympathy and low expectations around their disability, and may not have learned that disability is a natural part of life and an area where they can have pride. Getting to know others who have similar experiences can lead to friendships with peers who can support and mentor each other.

It's best if staff don't convey what youth with disabilities should do, feel, or be. In fact, it is best not to use the word "should" when discussing feelings and preferences. Everyone needs to develop their own attitudes and reactions. Far too often, people with disabilities, especially those with developmental disabilities, are told what they should be doing and feeling. The center is responsible for offering a variety of transitional opportunities to the youth; the youth are responsible for developing their own attitudes and making their own choices.

Create an environment where young people can feel and be safe, where any topic can be discussed, where everyone is treated with respect. Be honest in communication with young adults and require everyone participating in your programs to do the same. If an individual does not treat others with respect, challenge their behavior, so that youth with and without disabilities know that they are safe in the space created for them at your CIL. Set ground rules. If youth use inappropriate language, discuss alternative words. If someone is having a bad day, do all that can be done to support them; but it may be necessary to say that they need to go home if their words or actions are not respectful to all. It may be helpful to say that if anyone creates a serious problem, staff will not be calling the young adult's parents, but the police. The center is very important to hundreds of people and one person cannot be allowed to stop operations or harm others in any way. If the actions or words are not serious or harmful, a more positive strategy is to consider what the young adult is going through. Consider what can be done to help them, either through the center or other agencies. It may take some brainstorming with staff or other agencies to find the right approach.

It is a good idea for all staff to receive training on recognizing and responding to people with mental health concerns. Identifying behaviors and learning strategies will help to avoid problems before they happen. Contact the National Empowerment Center ([www.power2u.org](http://www.power2u.org)) and the National Alliance on Mental Illness ([www.nami.org](http://www.nami.org)).

Aside from considering any potential problems, it's paramount to have fun when working with youth. The environment needs to be enjoyable and staff needs to develop a sense of humor both when engaging youth and in responding to them. The

environment and activities have to be inviting for youth to even consider participating. Of course all the humor needs to be respectful and never targeted at an individual.

Some of the most fun activities for youth with and without disabilities can be simple, like making posters or buttons for a rally. Consider other activities, such as performing music, playing chess or other games, or just chatting. When there are people doing different things, whatever they enjoy doing, it is clear to youth that they get to choose what they want to do. Don't force people to participate, talk, or engage in a certain way. Youth often prefer informal, less structured activities. Let young adults plan and guide their activities or events.

## **Independent Living Skills, Self-Advocacy, and Systems Advocacy**

Think about topics or classes that seem to be a common area of need or interest to youth. Develop a curriculum that, either individually or in small workshop groups, can provide support to the independent living goals of youths. Financial management, cooking, riding a bus, decision making, negotiating a college environment, and job seeking and interviewing are some of the skills that many centers assist with.

An essential skill area for all people as they move into adulthood is self-advocacy. Self-advocacy often leads to broader skill sets as individuals mature in their understanding of the larger social and cultural issues that affect them as well as others. As you meet with youth and they share their lives, areas for advocacy or self-advocacy will naturally emerge. Take the time to discuss these advocacy issues and assist individuals or groups to stand up for their rights through self-advocacy and participation in the community's larger systems change issues. Involvement in the community is often an important step in developing leadership skills that become transferable to many aspects of independent living.

## **Outreach**

Take the time to plan for developing and expanding youth outreach. It sometimes doesn't work very well to invite youth to come to the CIL office, especially before they get to know you. However, offering recreational activities, such as inclusive tennis, basketball, and other outdoor activities are much more likely to be well-attended. Find those programs that might be run through outdoor programs, rehab centers, minority and other organizations, and collaborate with them. You might also build collaborations by attending meetings of disability organizations. Examples of specific organizations, coalitions, and groups include People First, Autism Council, United Cerebral Palsy, M. S. Society, Parent Center, Disability Law Center, Employment Partnership, NAMI, and the Legislative Coalition. Talk about what the CIL offers at those meetings, collaborate on activities, and recruit consumers, including youth.

Other meetings that can be attended for outreach and recruiting purposes include monthly meetings at schools, such as school counselor, social worker, or special education staff meetings. Provide flyers about the youth program. Parent-teacher

association meetings may be another avenue to recruit. Flyers can be sent home with students. Offer to speak in different classrooms at school, generally through the special education supervisor or transition coordinator.

Students may also tour the CIL as part of a community outing. During that visit, staff can provide a 20 – 30-minute sample of a workshop for independent living skills. Students may like it enough to come back for the full workshop or possibly volunteer so they can learn more about the workshop topic and disability in general.

Other agencies in the community that already serve youth may be looking for something in which to involve their youth. They may not be aware of the CIL. These agencies might include a teen center, recreation center, 4-H club, boy/girl scouts, or boys/girls club. If the center can connect with those agencies, it can provide a built-in target audience for the youth program.

Flyers can also be placed at the CIL, schools, home school associations, local ethnic and minority organizations, grocery stores, churches, state agencies, disability organizations, boys' and girls' clubs, student organizations, state assistive technology programs, universities, technical schools, colleges, health departments, community centers, doctors' offices, and the YMCA/YWCA. Articles and announcements about the center youth program and activities can also be placed in the CIL's and other disability newsletters, websites, and email distribution lists.

Radio, television and newspapers can be utilized through sending out articles and information about upcoming events. Often local public radio and newspapers will have a community calendar where public events can be listed at no charge.

Another way to connect with youth is through social media. Most young adults engage with social media. Youth activities can be listed on the center website. Consider developing a presence and continually updating the following social media:

- Facebook
- Twitter
- Instagram
- YouTube
- Pinterest
- LinkedIn
- Blogspot, Wordpress, or other blog platforms
- Website

Once the center program is successful, the young adults who participate will recruit their friends and classmates. Youth can spread the word at their school or can help the center do so. Word of mouth advertising is free and works well. It just takes time to build. The program will grow if it is well-planned, led by youth, and executed in a responsive way.

## Chapter Four: Fostering Youth Leadership

Involving youth in leadership opportunities increases the likelihood of successful transition; connects youth to their peers, staff, and other people in the community; helps youth feel more in control of their lives; improves their self-esteem; and enables them to learn new skills and have a position with responsibility. Young adults with disabilities often do not have the chance to participate in the important decisions that affect them, which contributes to feeling powerless. Some of the IEP and 504 meetings held around the country do not encourage the input of youth into their own life planning, much less in the community as a whole. Providing input and guidance into activities at the center will help youth develop confidence in their own opinions and feel valued. Try to meaningfully involve youth in all levels of the CIL, including strategic planning, developing policies, providing services, and evaluating activities. Youth involvement in all center operations will result in a stronger, more diverse, creative and effective organization.

An important aspect of bringing young people into leadership at centers and in the independent living movement is staying open to the topics that the next generation of leadership advances. The agenda or what young people want to do with the movement can look totally different from the ways things have been done in the past. It's vital to support people moving forward, even if there isn't agreement with what those steps are. Developing young leaders is essential to the long term success of the independent living movement and to the success of your CIL.

It's best for youth to set the agenda, or at a minimum, have authentic input into the agenda, for youth activities. Youth should be in the driver's seat in their own Independent Living Plan, similar to consumer control for adults with disabilities. They should also have input into youth activities. Accountability goes both ways. Remember that we are not only hiring a young person or creating a youth culture—we are sharing power with youth. What does sharing power look like? Sharing what's actually going on—transparency—instead of keeping decisions behind closed doors, is essential. Inform people about how decisions get made.

Create a plan for including and supporting youth in these leadership roles. Try to remember what it is like to be 19 and consider what youth need to do this work. Think about the center organizational chart and where youth can best be placed. Don't limit the youth to only those positions. Ask youth what they want to do, and find ways to fit their interests with positions as much as possible.

Young adults can begin by job shadowing to see how tasks are done. Let them take over when they are ready. Someone may start out as an assistant, but assign them specific tasks with increasing responsibilities to build some of the elements of leadership. Help them gradually move up when they are ready. Always provide mentorship and support.

Youth often challenge traditional ideas of leadership. Leadership can mean different things to different people. It can be the person who follows up with everyone, the

person who plans activities, or the person that orders the food. It often is a question of figuring out who has the skills and interest, where those skills and interests best plug in, and creating a collective agreement for what accountability looks like.

Commit to having at least one youth attend local, state, and national trainings and conferences, such as the annual conference by the National Council on Independent Living (NCIL), the Youth Leadership Forum, the annual conference by the Association of Programs for Rural Independent Living (APRIL), and any state-wide youth leadership gatherings. Invite the youth to visit ILRU.org and review the extensive resources at <http://www.ilru.org/topics/youth-transition>, the youth transition page. Youth will learn a lot by participating in these activities. Youth also have much to contribute. Consider submitting conference presentations including young adults, or helping them submit their own presentations.

When youth assume leadership roles, the center and the young adult both benefit. Allow youth to determine the best and most relevant youth activities and services. Youth provide good motivation for older staff. Young adults make the best peer counselors/trainers for other youth. Young adults know where to conduct outreach. When youth are in leadership roles, they will experience self-determination, and learn about something that improves their lives. They will better understand why their lives are the way they are, and how to make any desired changes. Learning how to be a leader will enhance self-esteem, confidence, knowledge, and skills.

Often as the young adult learns independent living and leadership skills, parents / guardians realize that independence is possible, perhaps for the first time. Some centers provide support groups or other activities for parents that enable learning, encouragement and growth. Supporting, sharing resource information, and learning from other parents who have children with different disabilities is often very beneficial. Parents can also be actively involved in community or legislative advocacy or in connecting with potential financial sponsors for the youth activities.

Your center is a facilitator that can assist youth with disabilities to move into new leadership roles, move into responsibility, and own the program, not just be the recipient. Start shifting youth into leadership and decision-making roles in every area of your center's operations. This will benefit youth with disabilities and strengthen the center in multiple ways.

## Chapter Five: Essential Functions of Peer Support<sup>2</sup>

Peer support is a required core service of centers for independent living under Title VII of the Rehabilitation Act as amended. It is such a cornerstone of the independent living movement that it's easy to take it for granted. To meet the requirements of this core service, some CILs focus on one-on-one peer relationships. Some centers provide peer support groups around various topics. Some are offered for specific groups of people such as youth, older adults, and specific disability populations. Others are more general. Some are modeled after the self-help approach of groups such as Alcoholics Anonymous, and others are more social or recreational in nature. Some centers have an organized group of volunteers with disabilities to be peer mentors, while others depend on the staff members who have disabilities to provide peer mentoring as a natural part of every interaction with a consumer. Some centers implement a mix of these strategies.

Whether your CIL prefers to take an informal or organized approach to this service, peer support that occurs in a relaxed and enjoyable way will go a long way toward attracting more youth to your CIL. Whether youth are receiving guidance, information, emotional support, or training, it can be especially helpful coming from a person who has already gone through the experiences.

Structured peer mentoring between individuals who are not legally adults offers some administrative and legal challenges, so consult with an attorney as you develop any formal peer mentoring services between youth. The CIL needs to be mindful of the role of parents or guardians with minors. Level of maturity and understanding of personal boundaries are critical factors for both staff and volunteers of a nonprofit organization.

Most centers find that the informal peer support that occurs as a natural by-product of getting youth together in the same activity is an effective way for the service to occur and can have a long-lasting impact on the individuals. Although formal mentoring is fine, if enjoyable recreational or community activities are offered, a lot more people may become involved. The friendships that develop through activities can naturally evolve into learning and maturing experiences. The individual and the peer can explore activities and become involved in the community together. Peers can also help with learning daily living skills, accessing resources, and achieving goals.

Many centers have also demonstrated that effective peer support can be provided to youth and young adults by young adults who are on the CIL's staff or part of an organized volunteer program. The CIL has authority to train, supervise, and evaluate the conduct of individuals that are employees or approved volunteers of the center. Trained young staff and volunteers can successfully provide the needed guidance,

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<sup>2</sup> Portions of this section excerpted from Michaels, B., Jones, D. L., McElwee, P. L., *Orientation to Independent Living for New CIL Personnel*, Independent Living Research Utilization, Houston, TX, 2015, p. 19 – 20.



support, referral to resources, and training for other young adults and youth with disabilities.

The support, acceptance and belief of peers are important for young adults with disabilities, as they often experience low expectations, rejection, and negative attitudes in the community. Peer support may improve feelings of confidence, self-worth, belonging and competence, leading to more independence and success. Peer mentors can assist with achieving independent living goals. Older adult employees or other mentors at your center can also be effective role models. The adults can show youth that older people are fun, by providing a role model of enjoyment without complaining or dictating. Youth can learn that life is cool with a disability.

Peer support can also be a positive experience for the volunteer mentors. Sometimes the mentor identifies and sets new personal goals which may include having a chance to “give back,” increasing their own advocacy and leadership skills, enhancing their knowledge of community resources and civil rights, and increasing their self-esteem and self-confidence.

Peer support also is beneficial for the CIL. Volunteer mentors share their knowledge, expertise, experience, and connections. Peer mentors with disabilities market and recruit within their personal networks when they speak about the center. The reach of the center is expanded into the community. There is never enough paid staff to do all of the work. Mentors help the center serve more people. When the CIL is the gathering place for the disability community in your area, everyone benefits. The CIL advocacy network is also expanded.

Key components of a structured peer mentor program include effective recruitment, training, supervision, evaluation, and recognition. Training topics may include information on independent living, the center, information and referral, the mentor program, communication, disability awareness, helping versus dependence, ethics and appropriate behavior, self-advocacy, goal planning, and program administration topics such as recordkeeping and identifying resources. For additional information, check out Arizona Bridge to Independent Living’s peer mentor training manual on the ILRU website at <http://www.ilru.org/resources-cil-core-services>.

The IL-NET also offers on-demand training on building an effective peer support program available at <http://www.ilru.org/training/building-effective-peer-support-program-proven-volunteer-model>. Enter “peer mentor” in the search box for even more resources.

Mentors typically work one-on-one with transition age youth to achieve their specific goals. The ideal is to have a slightly older or more experienced young person serve as the mentor. Teenagers are going to be more likely to speak openly to another young adult than they will be to speak to an older person. They are more likely to share personal information with someone closer to their age. Someone close to their own age can understand better. Youth can talk about things they are interested in and

activities they enjoy—music, media, events, and other things that they like. Once that bridge is established, then the mentoring can start.

Peer support can also happen effectively in a group. One center for independent living offers group peer support sessions where a group of young men with disabilities meet on Saturdays and sit around and talk. Staff members don't always stay in the room so that consumers can feel free to say what they want to say.

Your center may have a specialist who works specifically in youth services, or may rely on volunteers. Whoever is hired or assigned to work with youth at the center must be mature. Although forming more friendships is a goal, this person needs to understand boundaries and how to recognize potential sticky situations. Facebook and other social media make it easy to cross the lines where consumers may ask for help over the weekend or become overly friendly. People with disabilities often have not been taught or encouraged to set appropriate boundaries. Staff members need to trust their own instincts when things are going beyond peer support or friendship. They may need to ask their manager or director for help. It is usually beneficial to keep work and home life separate. Certainly the more experienced mentor or staff person must avoid any actual situation or even the appearance of the development of a sexual relationship. If such feelings are developing, talk to the manager immediately and build safeguards into the relationship. If both the consumer and the staff person are consenting adults, there is still a risk of misusing the trust and influence that a mentor builds.

Mentors and mentees often move on to contribute to their communities by volunteering, furthering their education, finding jobs, and becoming effective disability advocates. Although there are sometimes barriers to offering an organized peer mentor program, the benefits to the mentors, mentees, the center, and the community are immense.

## Chapter Six: Utilizing Volunteers

Volunteers can help make a youth program or services work, even with a small staff base. When there is limited funding, the use of volunteers can be crucial and beneficial. Volunteers can help with many activities, such as facilitating games, chaperoning outings, presenting at conferences or workshops, writing announcements and distributing flyers, and assisting with accommodation needs.

Volunteers often enjoy helping out with specific tasks, especially when they feel that they're making a difference. There are other benefits for the volunteer, including fostering friendships, developing skills, increasing socialization, and giving back to the disability community. Sometimes volunteering leads to paid employment.

Staff needs change all of the time. To begin considering where volunteers could be placed, conduct an inventory of where volunteer opportunities are within the center. By serving youth, the center is moving into different areas with new partners and alliances. Some things will need to be rethought and redone.

After inventorying where the needs are, consider what type of volunteers are needed. Which skills are necessary? What will be their minimum level of commitment? Is age a factor in the placement of the volunteer?

Think about how to make it worthwhile for volunteers to fulfill their commitment. Consider how to market the center. Let potential volunteers know why they are needed, why IL is worthwhile, why they should choose to volunteer at the center, and how they will benefit.

You can recruit volunteers through presentations at high schools, key clubs, recreational centers, and other places where youth hang out. Ask if flyers can be posted. Lots of high schools require community service to graduate. Find out who administers that program and how you can recruit students to community service at your CIL. Advertise through social media, such as the CIL website, Facebook, Twitter, LinkedIn, Pinterest, blog, and newsletter.

Colleges and universities are also good places to recruit volunteers. Check to see if they have a service center or volunteer office. While high school students have much to offer, older young adults may provide a bit more experience.

Let potential volunteers know what will be expected of them, how often they are needed, and how long you expect them to participate as a minimum commitment. They will need to know the tasks, hours, and time required. It may be useful to describe the expectations for the volunteer position in writing so that a CIL staff person can go over the document with potential volunteers, determine their interest/abilities and answer their questions. Try to get back to potential volunteers promptly when they express an interest.

Volunteers will need to go through a background check, be provided with orientation to the CIL and IL philosophy, and receive training in their responsibilities. When you are approached to provide community service hours related to a plea bargain or judgment in a legal situation, this background check becomes even more necessary. You must reduce the risk of bringing someone into the center whose history indicates they might take advantage of a consumer.

On rare occasions, a person who is already trained will offer their services. However, in most cases, volunteers will lack knowledge and skills. You know that people in the community often have biases and attitudes about people with disabilities. Even if the volunteers have a disability, they may have their own misperceptions about disability rights and other disability issues. Training will help volunteers to feel more comfortable on the job, and understand the center philosophy, services, staff, and consumers. Volunteers will need to be taught what to do, how to do it, what not to do or say, and what to do in case of an emergency. Training should cover disability awareness, sensitivity, center policies and procedures, and confidentiality. Some centers develop a volunteer handbook which addresses this information. Make sure that knowledgeable staff members are available to provide support and answer questions, and to provide feedback when they observe an area where the volunteer lacks information.

Even though volunteers may be hesitant at first, and think that they are only completing their community service hours, they often become involved with the center. Youth frequently ask to be contacted whenever help with other activities is needed. It's fairly easy to acquire a database of volunteers. Take the time to ask the youth, as you sign off on their hours, if they are interested in returning and add their name to the list. If one youth participates or works at the center, they'll usually bring friends.

When good volunteers are found, hold on to them. The training and knowledge of experienced volunteers is not easy to replace. Think about ways to maintain and engage them. Treat volunteers with respect and involve them in meaningful and varied activities. Place volunteers in the areas or activities they are most interested in, if possible. Let them participate in planning activities and decision making. The opportunity to socialize at events may be important to volunteers, from youth to retirees. Reward volunteers frequently with recognition, awards, written notes of encouragement, invitations to organization events and verbal thanks for a job well-done. Volunteers should know that they are a valued part of the organization.

## Chapter Seven: Cultivating Key Partners and Collaborators

### Partnerships with Schools and Vocational Rehabilitation

Public schools operate under their own procedures, policies, and requirements. Each school district is unique in the way that things are done. The vocational rehabilitation agency (VR) also is regulated with its own procedures and requirements, although VR counselors are somewhat individual in their approach to working with consumers. However, given these constraints, common ground can be found. For one thing, all three organizations (CIL, VR, schools) have the mandate, the desire and the goal to help youth succeed. When getting involved with VR and schools, it may help to keep the focus on commonalities, the goal of more effectively serving youth with disabilities, and forming good partnerships.

When setting up a partnership with a school, start with established relationships. It will be easier and faster if the school already has knowledge of the center services. If no good relationship exists, find the right people who are the champions and willing to put themselves out there in schools. The special education directors or transition coordinators are probably the best people to contact. The State Department of Education is also a good potential partner. The VR agency may be able to open some doors to schools that could be collaborative. The center may obtain widely different levels of cooperation, depending on the school and district.

Think about how the center can benefit the school. Do teachers need assistance with developing good transition services? Will they benefit from in-service training? Can the center provide independent living skills and disability awareness workshops and other training to students with and without disabilities? Can they provide one-on-one interaction with students? Can they connect students with disabilities to other services and resources within the community? Can the center provide other needed services?

Be clear about the requirements each partner has, and try to meld those together to support each organization. Monthly meetings to plan and problem-solve with all parties are beneficial. Figure out ways to measure each student's progress. When centers are working with school districts, find out what their needs are for their students, especially within the constraints of their calendar year. Discuss whether it's best to set up something for a quarter, a trimester, or other timeframe. Find out their requirements for earning credits.

Some centers have coordinators embedded in the schools. The coordinators from one CIL teaches the *Living Well with a Disability* curriculum that covers setting goals, problem solving, healthy reactions and communication, beating the blues, seeking information, finding additional services and opportunities, physical activities and their importance, eating well, and the importance of self-advocacy. The coordinators also connect students to resources, provide teacher and student trainings, and interact one-on-one with students. You can find more information in the form of on-demand training

about this program at <http://www.ilru.org/training/building-effective-comprehensive-cil-youth-program>.

Another center developed their curriculum with VR and the school district. It is academic based, but also has soft skills, pre-employment skills, and an employment portion that matches students' interests. Five students are selected from the three local high schools and the vocational school to participate in the program. It is small to make sure that it is cost effective, as a fee-for-service program. There is an advisory group comprised of the CIL, VR, school administrators, and counselors that meets monthly to plan and brainstorm any student difficulties. It is a win-win for all three agencies. It is a good incentive to keep students in school, where they earn credits and make progress toward their employment and academic goals.

Yet another center started a program in collaboration with their local university. The university's human resource program provides internships for their students to work one-on-one with the center's young adults who are transitioning from high school to employment. Human resource professionals work with the youth on career exploration, interviews, job seeking skills training, and resume development. Once the young adults are ready, the professionals help them find a job.

The center that has coordinators embedded in the school districts had a competitive, non-cooperative relationship with VR for a number of years. Eventually the state's CILs realized that if VR and CILs were both going to successfully meet the needs of people with disabilities, it had to be done together. IL directors were challenged to meet with VR regional managers to collaboratively develop a specific plan for each local region to meet the needs of individuals with disabilities. The one theme that the 12 regional managers kept coming back to was that there had to be a way to meet the immediate needs for consumers who came into a workforce center. An IL specialist was placed in each of the 12 workforce centers. The IL specialists are set up with a mobile office with cell phones, laptops and printers to provide information, resources and forms. A project-specific website was developed with curriculum and resources. The methodology is designed to meet both the vocational rehabilitation and independent living needs of consumers. The purpose was to build local service capacity in mutual partnership to advance the employment and independent living goals of citizens with disabilities. The IL staff has become an essential part of the VR intake process.

The center that offers a Saturday peer support group for young men applied for and received a \$50,000 AmeriCorps grant. The main focus is on selecting young members with disabilities statewide. The center provides employment and soft skills training with them all year long. Several of their current staff started out as AmeriCorps members. The center also develops and presents skits with AmeriCorps members. Their AmeriCorps members take some of the things that happen to them in everyday situations and turn them into funny, interesting, or thought-provoking skits. They often are able to present at different schools through the teachers, parents, or students that they know. This starts conversations and brings in new consumers.

Another center is involved with an online free public accredited K – 12 school. The school has 1,535 students in special education and 900 of transition age with two people to serve them. A lot of students were struggling with social skills, isolation, transportation, and other areas. The CIL provides fee-for-service training in these areas, adapted to each student's needs. They also provide person-centered planning.

On-demand video presentations from all these centers regarding their youth programs can be found at <http://www.ilru.org/training/expanding-cil-capacity-through-youth-transition-services-collaborating-with-school>

## Ideas for New Partners

Capacity building is about development and growth, but also about networking, partners, and collaboration. There are a number of potential new partnerships with organizations around transition. Collaborations enhance services within the community and provide more options for consumers. CILs can make their services more accessible and expand their reach by working with partners. Collaboration provides a way to take CIL expertise to another organization and receive benefit in return. Collaborating with partners can provide more adults and youth for center activities. Partners can provide many services that youth can be connected to for employment internships and jobs. Youth can benefit from partnerships arranged by centers in many different areas.

Recreational organizations such as parks, zoos, stadiums, sports clubs, university or college recreation departments, and fun centers offer outdoor activities for people with and without disabilities. Rehabilitation facilities may offer recreational activities and peer support groups. Community centers provide great opportunities to collaborate on activities that will attract youth. Often the recreational organization struggles with how to provide accessible options, and the CIL can assist them in that area. Providing fun activities, such as adaptive rowing, snow and water skiing, biking, wheelchair basketball and soccer, horseback riding, boating, fishing, photography, art, candy making, glass blowing, tennis, ping pong, swimming, wheelchair hockey and rugby, street hockey, hunting, or perhaps a recreational clinic, will bring in many more youth. A recreational agency may already have facilities, equipment, and participants, but may not have expertise in adapting their activities to provide access to various disabilities. Adding youth with disabilities and expanding their access is a win-win.

There are many other organizations that would be excellent partners. Find out which organization or department is receiving Title V Maternal and Child Health Services Block Grant funding for children with special health care needs. Investigate whether a new collaboration could be formed around transition services. Title V organizations are often geared more towards young children, but transition is still a part of their services. There is a good chance that the Title V folks need to figure out how to make their transition services more effective. The CIL may be able to receive a portion of Title V funding to provide these needed transition services.

Other partners could include community action agencies, family or parent centers, the corporate world for disability mentoring day and employment exploration, homeless coalitions, intermediate units, special education programs, disability organizations, the university center for excellence in developmental disabilities, and children's hospitals.

It is wise for staff to learn about, connect with, and build good relationships with the disability resource centers or disability student centers in all local colleges, technical colleges, and universities. If staff know the right people to contact, along with the services offered on each campus, it will be easier to connect with students with disabilities. If advocacy or knowledge is needed by the college or university, the CIL may offer information and advocacy to assure that students receive needed accommodations.

Universities are also excellent to connect with for other reasons. Almost any department has university students that may be looking for projects or internships, such as human resources, business, social work, and psychology. Faculties are usually eager for their students to have real world experience. Students may not necessarily need to be paid. The university may pay the CIL several thousand dollars to run a portion of their training program, or help with a research grant initiative.

Remember that one of your goals is to facilitate the development of leaders. Working with the colleges and universities in assisting students to learn how to serve on boards and councils has the double benefit of building their resume and of assuring that there are qualified people with disabilities to serve where the disability community needs to be represented—including on the CIL board of directors.

There are more than 30 states with Youth Leadership Forums that would make excellent partners with center youth programs. Collaborating with these forums provides access to a pool of youth with disabilities. Their purpose is to improve the employment and independent living outcomes of youth with disabilities transitioning from high school, and teach leadership skills. Hundreds of youth with disabilities go through the youth leadership forum every summer across the country. More information, with state chapter contacts, can be found on the Association of Youth Leadership Forums website at <http://www.nationalAYLF.org>.

Other organizations that may need help with increasing accessibility for youth with disabilities include teen centers, youth organizations, the foster care system, boys' and girls' clubs, and boy and girl scouts. One center asked their YMCA if they would be willing to hire an inclusion specialist if the center would help to financially support that position for two years. The agreement was that the YMCA would come up with a plan to support that position indefinitely. After the YMCA saw how helpful this position was, an inclusion specialist was hired at every location to help anytime a person with a disability needed an accommodation. Some other examples of potential youth program partners include County 4-H, Family/Parent Centers and Youth Centers. *Kids Included Together* is a curriculum some centers use to train community members around best inclusion practices. More information may be found at [www.kitonline.org](http://www.kitonline.org).



Employers in the community are potential collaborative partners. Building partnerships with employers is the key to good employment, job shadowing, mentoring, and volunteer opportunities for youth. One center asks different sites if they will allow students or consumers to job shadow. Job shadowing helps consumers or youth see exactly what different jobs entail and determine the best career to pursue. These agencies may also be willing to participate in National Mentoring Month, described at [www.mentoring.org](http://www.mentoring.org). The American Association of People with Disabilities, ([www.aapd.com](http://www.aapd.com)) has many helpful resources on national mentoring day available to potential coordinators and partners. They can also provide information on job shadowing and other resources.

Consider contacting the state AmeriCorps office. Offices may be found on the national website at [www.nationalservice.gov/programs/ Americorps](http://www.nationalservice.gov/programs/ Americorps). It may be possible to recruit an intern to work in the center. It may also be possible to apply for state or federal funding to develop youth programs utilizing volunteers. Because these funds provide staff for only a year or two, this could be supplemental funding. Because there are advantages to college aged students or graduates related to their student loans, AmeriCorps volunteers may be youth who can be placed in leadership and decision-making roles.

Collaborations are usually attractive to funders. Funders like to see that their dollar is stretched further, funding more organizations. It can be helpful to write proposals with partners. Collaborative partners provide a way to divide the work and share funding opportunities.

Another idea for partnerships is with those organizations working on the public policy side of health care and development, especially when it comes to serving people with disabilities. Other disability-focused organizations can be encouraged to support public policy that benefits people with disabilities, including youth. It is important that IL philosophy and the youth perspective are part of public policy discussions and decisions.

## Working with Partners

Cultivating partners takes a bit of persistence and follow through. For the most part, approached agencies will be interested in partnering for the betterment of mutual consumers. There may be a few agencies or individuals who are a little territorial, defensive, or difficult to deal with. If this is the case, don't continue down that path. Find a better way.

A great way to start to defuse a history of animosity between agencies is for the CIL to very clearly present itself as an equal resource to the cadre of services an agency may already have available. If the agency knows the CIL is not there to tell them how to do their job, tell them that they were doing their job badly, or to tell them that they weren't being successful, that may go a long way to improving the relationship. Offer the CIL as a resource to add to their tool kit. Centers may be viewed as a one-stop shop that can help students with independence, transportation, daily living skills, grooming, and

more. Keep the focus on commonalities and common goals. Build and change the system through positive relationships. As advocates we know how to take out more confrontational tools when needed, but if we can start the relationship on a positive note we will have more cooperative partners.

If the consumer is not happy with the services from vocational rehabilitation or another service agency, employ tact. Bring the team together and have a discussion about what is working and what isn't working. Encourage consumers to speak up and express their issues. The main concern is the consumers' desires, and making sure that all agencies are adhering to the consumers' plans.

Occasionally there may be a power differential that happens with large agencies. A respectful and gentle reminder that the center comes to the table as an equal may not be out of place. CILs have competencies, unique skills, and something valuable to deliver to the shared consumers.

In some situations, working collaboratively may be challenging. It may be that a person with power and authority does not want to give that up. For the good of the consumer, centers may need to be the ones to calmly advocate with and for the consumer and consumer rights. Access to more services will benefit consumers to obtain better jobs and live more independent lives. Sometimes a shared staff lunch with vocational rehabilitation or other agencies is a good way to smooth differences, make introductions and learn about services, resulting in increased referrals. Maintain a 'yes first' attitude. Always come to each situation believing that a way can be found to get it done, even without knowing how. Things will work out with persistent effort.

## Community Inclusion

Promoting equal access is a key role of CILs and is an approach that will greatly benefit youth. As a CIL you must continually seek ways to assist community services to be accessible to the youth they serve. There are many collaborative approaches to promoting access and inclusion. Some centers have established an inclusion task force with other agencies. Key players brainstorm how to educate community members and promote inclusion across race, ethnicity, disability, sexual orientation, gender, and age. These centers develop and/or attend inclusion conferences to learn best practices, develop professional relationships, establish linkages with other agencies and utilize resources.

One of the most important things to communicate to community partners is that individuals with disabilities need to feel accepted. Physical and program barriers that block access also communicate that people who can't access that service are not accepted. Even though the ADA has been law since 1990, and 504 compliance was required before that, not all public buildings meet those requirements. Not all services provide accessible information. Fortunately, centers excel in accessibility, equality, and inclusion. It may help the partners see the importance of removing barriers if you help them understand that inclusion is about acceptance and offer your CIL's expertise about disability and access.

## Chapter Eight: Providing Services and Activities

Centers facilitate empowerment for adults with disabilities on a regular basis. Empowerment and coming into one's own sense of self is a process that can be started at any age. CILs can encourage and assist adolescents to claim and maintain their authority when they are dealing with schools, VR, parents, health care providers, and other systems and processes. It may be a bit of a transition from letting parents and professionals make all of the decisions to full empowerment for youth. Arguably the best thing that can happen to young persons with disabilities is to learn how to be self-advocates and to make their own choices and decisions so that, as they enter post-secondary life and legal age, they are ready to have control over their lives.

It's important to start working with youth early, around the age of 14, because decision-making skills are developmental. Set some goals to achieve, no matter how small, and try to engage youth in that decision-making process. Make sure that the young person is actively managing their own IEP, including the decisions that are being made (see the IEP section for more information). Discuss with youth who else can provide support, whether it is VR, guidance counselors, or other community-based supports; and get them connected.

The CIL described in chapter seven that has coordinators embedded in school districts developed and conducted a statewide survey of youth with disabilities with 15 different school districts to find out what their transition experience was like, what kind of services they received, and their satisfaction levels. Students said the thing most lacking was that the school simply did not listen to them.

School districts, parents, and others may need to be reminded of the mantra, "nothing about us without us." What does the student want? Has the student been asked? The role of the center is to ask the student, "What would you like to do? What do you think about this idea?" Ask these questions *before* the meeting with adults and assist the youth with writing their ideas down. If they don't read, assist them to develop a pictorial reminder card. Let them practice telling you what they want so they are ready when you ask that question with others in the meeting. Consider parent education, including allowing the youth to make his or her own decisions, what they should be getting out of the IEP or 504 plan, and what it looks like to be supported within the community.

### Crucial First Steps in Program Development

First of all, try to figure out what activities young adults want, through surveys or other means. In addition to youth activities, involve them in the larger disability community. Plan what the desired future will look like after completing school by ensuring that appropriate services are provided while they are in the school. Enable youth to fully participate and direct student IEP meetings and other activities. Help them to plan the supports they will need.

CILs have found great success when incorporating Person-Centered Planning into a young adult's services. While there are many different types of Person-Centered Planning methods, most use either MAPS or PATH, or a hybrid of the two. Information about Person-Centered Planning can be found readily online, but all methods require a significant investment of time and require appropriate funding. The Lehigh Valley Center for Independent Living (LVCIL) reports that Person-Centered Planning has been one of the most integral parts of their success in developing transition programming. LVCIL has seen Person-Centered Plans incorporated into students' IEPs, and notes that they provide a much clearer path for services for each young adult in their programming. Funders of the LVCIL are also very attracted to the concept and final plans. Most importantly, Person-Centered Plans promote consumer control and provide great motivation for each young adult.

If the investment of Person-Centered Planning is not an immediate option, consider doing simple mapping with youth. They can start mapping with the date of their birth, with milestones and accomplishments. Then move on to map where they want to go, including relationships, jobs, favorite places, and living situations. It's best to let them choose whichever form of media or communication they want to use, including drawing, writing, acting, etc.

Another variation is to list four things that youth want to do. Identify the barriers that might keep them from getting there, the knowledge that is needed, and the people in the person's network that can help them achieve their dreams. Establish realistic timelines and follow-up.

## Examples of CIL Youth Programs

There are many examples of CIL youth programs, activities, and services. Some from actual CILs include:

### *Community Training and Awareness*

- Schools – students with and without disabilities
- Conferences – students, parents, service providers, and employers
- Community events – consumers, families, providers, and the general public

### *Workshops*

- *Living Well with a Disability*
- Obtaining and maintaining good health and wellness
- Interpersonal development/self esteem
- Effective self-advocacy
- Taking ownership and self-led IEP
- Disability awareness
- Adult benefits
- Disability culture and pride
- Advocacy for accessibility

- Internet and personal safety
- Independent living
- Preparing for employment
- Conflict resolution
- What to expect at college
- Transition series
- Parents matter
- Making proud choices (sexuality)

### *IL Skills Classes*

- Cooking
- Meal planning
- Healthy relationships
- Money management
- Transportation/bus
- Hygiene, personal needs
- Interpersonal skills
- How to supervise direct support staff
- Adult disability benefits
- Legislative/policy process

### *Annual Youth & Parent Retreat*

- One weekend a year
- Caters to 14 – 21 year olds with a separate track/retreat for their parents.
- All activities planned by a Youth Advisory Council.

### *Youth Advisory Council*

- Developed for youth program to ensure input from the targeted community.
- Composed of individuals between the ages of 18 and 30 who have received services at some point.
- Meets quarterly either face to face or via teleconference.
- Responsible for planning the annual youth/parent retreat each year. Determines the theme, food, and dates based on campground availability. Also determines the speakers and activities to be offered, including the parent section of the retreat.

### *Camps*

- Youth leadership and development
- Transition to independent living (social skills, cooking, IL skills, etc.)
- Dream manager – finding and achieving goals and dreams
- Recreational activities through the center and different agencies

### *Other programs*

- Youth leadership
- Mentor programs
- Job clubs
- “IL in Action”
- Recreation
- “Community Connections”
- Advocacy day at the state capitol
- 4-H
- Girl/Boy Scouts
- YMCA
- Local high schools

### *Other Services*

- Imbedding CIL staff in VR and schools
- Web-based online discussion boards
- Transition with technology
- General information, referral, and assistance

Many centers use the *Living Well with a Disability* curriculum, a ten-week wellness workshop that helps participants achieve full participation through health promotion and maintenance activities. The curriculum is evidence-based and certified as Medicaid reimbursable in some states. Some centers teach it in schools during regular school hours and the students receive credits. It was developed by the University of Montana and has been demonstrated to show real cost savings as far as medical services are concerned. More information about the curriculum can be found at: <http://livingandworkingwell.ruralinstitute.umt.edu/>.

Youth Transition services to postsecondary life must be provided in the context of written goals, either in a formal Independent Living Plan or, if the consumer waives the plan, in other written form that captures the goal or purpose for the service for the individual consumer.

## Chapter Nine: Health Care Transition and Building a "Medical Home"

Health care transition is equally important as school transition in youth services. Sometimes after youth leave school, they discover that they do not have medical insurance or a doctor. Without insurance, youth often do not seek treatment when needed, fill a prescription, or take care of medical issues. Parents may have made all appointments and taken care of all health-related needs.

Center staff can help young adults prepare for health care transition, including learning how to access quality health care with new providers and manage their medical needs. It will be easier if young adults have been moving towards self-advocacy and managing their own health care already. In addition to finding good providers, young adults need to understand their disability, how it impacts them individually, and how it may change over time, with maintenance and preventative care techniques.

Youth should also be able to identify signs and symptoms of personal health emergencies, when to seek treatment, and have contact information for health care providers that is easy to find. If the young adult uses assistive technology devices, they should learn who provides services and how/when/where to maintain or repair the devices. It will also be necessary to know why, when, and how often to take medication, and who to call for questions or help. The school nurse, doctor, and therapists can be asked to assist with transition planning around medical issues.

Another aspect of health care transition is self-advocacy. The young person should know how to ask for accommodations, if needed, what their rights are, when to speak up, how to contact disability advocacy organizations, and when to disclose information.

More information about health care transition can be found at:

[www.gottransition.org/youthfamilies/index.cfm](http://www.gottransition.org/youthfamilies/index.cfm). The Pennsylvania Department of Health has developed a 46-page health care checklist: *Transition to Adult Living*. This checklist can be found at <https://www.achieva.info/files/Resources/Education/Transitiontoadultlivinginpennsylvania.pdf>.

### Medical Home

It is a good idea for everyone, but especially persons with disabilities, to establish a "medical home," where they can discuss and manage their health care needs with caring knowledgeable physicians. Don't let the term confuse you—it's not a place to live. It is a model of health care that responds to the individual needs of the patient. A medical home is a widely accepted model or philosophy of primary care that is patient-centered, comprehensive, team-based, accessible, and coordinated. The focus is on quality and safety. While the term comes out of the medical community, the concept is a good fit with independent living. The medical home is a partnership between patients and their primary care clinic or physician based on mutual trust. In a good medical home, the patient feels safe and supported by the physician, nurse, and other staff,

who partner with the patient in coordinating care. The doctor exchanges information with the young adult honestly and respectfully. Both doctor and patient learn from each other. Good medical homes provide resources and connections to additional support organizations, services, and medical information for all stages of growth and development. Medical homes provide patients with all of their needed support services, and more than likely work as a team with other organizations in the community. A good medical home will work with the local CIL to make sure that needed resources are available to patients. The medical home partnership promotes health and quality of life as youth grow and develop into adults. More information about medical homes can be found at [www.pcpcc.org/about/medical-home](http://www.pcpcc.org/about/medical-home).

It is better for youth to see the same primary care physician and staff consistently. Physicians better understand their patients and their disabilities if they are seen repeatedly. When youth visit their doctor's office, it's usually best to bring a list of questions. Most doctors don't know what their patients need, and what they are trying to achieve personally, unless they are told. It's best for youth to be completely honest so their doctor can best understand their current physical and emotional health conditions. Information should be shared about any health changes. CIL staff can assist the young adult in learning and applying these strategies for talking with their doctor and other medical providers.

CIL staff can ask about community resources that may help the youth. Youth can be encouraged to show appreciation to a good doctor and staff. Medical personnel frequently hear complaints, but usually not compliments. It is encouraging and helpful to know that patients appreciate their efforts.

All youth deserve a positive relationship with their physician. If there are not good medical homes available in the community, the CIL might conduct outreach to physicians to encourage them to adopt the medical home model. Physicians may also need to be recruited to accept Medicaid, which is often the only insurance that youths with disabilities have. Building a medical home usually means enhancing skills, improving quality, integrating partnerships with patients and collaborating with other health care providers. The state American Academy of Pediatrics ([www.aap.org](http://www.aap.org)) and other medical associations may be willing to assist with this endeavor.



## Chapter Ten: Fostering Effective Youth-Led IEP Meetings

Students may need to be encouraged to fully participate in their individualized education program (IEP) meetings. They may have been attending these meetings all their lives but may not have been encouraged to take a lead role. Some students may be shy or passive, so the CIL might facilitate their participation by continually asking them what they think, what would they like to do, and how they feel about the choices. Other students may not feel empowered or in charge. They may have trouble learning to be self-advocates when they are at the table with parents, teachers, and other authority figures. Assist students to come out of the shadows, if needed.

Explore the big questions with youth in order to prepare them for their IEP meeting. This is one of the ways the center can really begin to draw them out. Ask questions such as, “What do you want your life to look like? What does that picture look like in the future? What school do you want to go to or what job do you want to have? What do you want to do for fun? Who do you want to take along with you?” Begin to plant seeds so that the young person starts to think about these things and begins to realize that they really do have a say in what happens to them. If the student is going to sit back and let things be done to them, then they are not going to be very satisfied with the outcome. The decisions that 14 and 15-year old youth make now will have a direct impact on their future.

One of the most effective things about CILs is their strengths-based approach. One CIL director tells the following story about his goddaughter with Down syndrome. One time he and her mother were sitting in an IEP meeting with teachers, school administrators, the special education teacher, and other team members. Each member of the education team, in turn, was sharing what was “wrong” with the student. One said, “In my class she doesn't do this very well either or she really has a challenge with this.” The CIL person finally leaned over to the student's mother and said, “Who are they talking about? You know, that's not the daughter that I know. That's not my goddaughter.” She said, “I know. It's very disturbing to me, too.” The CIL director said, “You have got to put a stop to this. You know, this is your meeting.” So she raised her hand and said, “You have my daughter six hours a day in your classroom. Where do you think she is the other 18 hours of the day? She's at home with us. Don't you think we know that there are difficult situations for her? We also trust that you're the professionals in the education field. You know how to meet those challenges.” She added, “From now on, moving forward, no more negative statements. We're going to start over again and from each one of you I want to hear you say something positive about my daughter.”

They were stunned. Finally, the art teacher said, “In my art class she loves tactile stuff. She loves the papier-mâché. She loves getting in there and getting her hands gooey.” The geography teacher said, “In my class she's really good with maps. She can read a map like nobody's business.” Then a conversation started taking place between the art teacher and the geography teacher. They came up with an idea for extra credit where the student can use the papier-mâché to make topographical maps. The whole meeting was changed.

As a representative from a CIL, you can proactively assist the student to prepare the content he or she wants to present at the meeting. If you wait until the professionals gear up, the youth may be shy about speaking. The conversations about where the youth wants to be in the future can be captured in writing or pictures on notes that the youth brings to the meeting. Practice with the student ahead of time. Encourage taking charge of the meeting, thanking everyone for being there, then presenting his or her ideas without waiting for the teachers to take over.

Besides trying to keep IEP meetings positive and solution-focused, CIL representatives need to be educated on the relevant laws to equalize knowledge and power. Staff of the CIL will also be a more effective part of an IEP team if they understand the school's applicable laws and regulations. If CIL personnel are prepared, they cannot be subordinated in IEP and other meetings because of a lack of knowledge. For example, if schools state that they don't need to provide requested services or equipment, CIL staff can quote the Individuals with Disabilities Education Act (IDEA). If the IEP is already filled out with the expectation that the parent will just sign without adequate time to look it over, tell the school that this is not how it works. Parents need to take the IEP home with them, review it, ask questions, and then reconvene with the team.

Even though schools may have the best interests of students at heart, they are almost always underfunded. Teachers and counselors may be strongly discouraged from including assistive technology and other types of services that cost money in the IEP. Center staff, parents, and especially youth with disabilities need to understand the rights and the laws that support the youth's request. Youth with disabilities deserve to receive the best possible services and education.

It may be very helpful to ask for a blank copy of the transition page of the IEP in advance of the meeting. Review the page and ask youth what they want. In the meeting staff can encourage the youth to bring up what was discussed. Sometimes the school will just flip right past the transition page without any contemplation of needs, unless the center or student asks them to stop.

Another consideration with the IEP is whether or not the student is aiming for a high school diploma or a certificate / occupational track. It's always best, if possible, to select the diploma track option that opens so many more doors for students. Students can try for a GED later, but it can be a very difficult test, and time consuming to obtain. It is often too late to change tracks in high school. A lot of teachers don't know the students with disabilities; sometimes they have never even met them. It's very important for centers and parents to be involved with the IEP in eighth grade and attend junior high meetings. If the wrong track is selected, it may be overwhelming or impossible for a student to catch up missing credits to obtain a diploma. If students take the classes in ninth grade and fail, they can still change from the diploma track to the certificate track, but not from the certificate to the diploma track. If the teacher states that the student's test scores are too low, the CIL can emphasize that the student needs the least restrictive environment in a fully inclusive classroom. The CIL can also ensure that students are provided with the needed accommodations when tests are given. Teachers may believe that they are doing their students a favor

because the certificate track is easier, but it will prevent them from being able to attend a junior college or further their education later. Often job opportunities are limited if the individuals don't have a diploma. It's also disheartening to students with disabilities to see their peers advancing while they are left behind. Being placed on the wrong track is one of the ways that students with disabilities get lost in the system. Check the options that are offered in your state. Make sure that the IEP reflects what is best for the student, not necessarily the easiest choice and preference of the school or teacher.

Assist youths to develop a personal file so they can begin to keep their own records. The files can travel with them when they leave high school and transfer to a post-secondary setting. Files should contain not just their educational records, but pertinent medical records, a copy of their birth certificate, social security card, and other items that may be necessary as they move to the post-secondary setting. Emphasize to the youths how important it is to keep these records secure and confidential, but to have them when they need them to transfer to a college or university or to get a job.

If youths are planning on attending college, contact the local college disability resource or services office. Some college disability office staff will attend IEP meetings as the student nears transition. It never hurts to ask.

## Chapter Eleven: Preparing Youth for College

College will enhance employment opportunities and the likelihood of obtaining higher salaries for young adults with disabilities. College also enables independence, critical thinking, social skills, and knowledge acquisition. Youth with disabilities need to start preparing to attend college while they are in high school.

When youth with disabilities attend college, they will no longer have an IEP (but they may be able to use their old IEP to establish services at the college disability resource center). Their rights and requests for accommodations will be covered under section 504 of the Rehabilitation Act and Title II of the Americans with Disabilities Act. Although these laws apply to both school districts and postsecondary schools, the responsibilities of colleges are significantly different.

Colleges are required to provide academic adjustments at no charge and accessible housing at the same cost as others pay. The school must be informed that the student has a disability and needs an academic adjustment or accommodation. The college is not required to assess students with disabilities' needs or identify them as having disabilities. Students need to understand that it is their responsibility to identify themselves and request services and/or accommodations. Most colleges and universities have a disability resource or service center that provides accommodations.

The student should get a copy of his or her last IEP, to help when discussing accommodations at the college. Some community colleges and universities will accept an IEP to establish services, but some require a new form to be filled out by a doctor, or an assessment to be completed. Ideally, that should occur early in the college enrollment process. The ideal is for students to have their needed accommodations in place when they start college. If requests are not made until registration time, there may be a delay. The college will have many students with disabilities to accommodate, and be very busy at the beginning of semesters.

It is useful for center staff to establish and maintain a connection with local colleges and universities to learn about their services for students with disabilities. Centers for independent living can teach students about resources and help them connect to the right disability services coordinator early to ensure that accommodation needs are met. The college disability services staff may strategize with the center and the student about those accommodations. Some college disability centers will make presentations to high school students and attend their IEP meetings. Colleges and universities vary in the type and amount of supports and services.

Parents and young adults need to know that once they get to college, there is no more free education. Applicants will need to fill out an application for federal student aid (FAFSA) form, to see if they are eligible for financial aid. The application can be found online at: <https://fafsa.ed.gov>. Parent income will count until the student is 24. The federal deadline is often months in advance, but applicants should check with their college.

Once students turn 18, if they are on SSI or SSDI, there are many work incentives available to them. The student should meet with a VR counselor to learn about these before their 18th birthday. Vocational rehabilitation will often pay for some college, accommodations and books for eligible recipients. Attending college must be one of the students' goals to acquire this support.

Youth may also consider applying for AmeriCorps. After the student finishes 1700 hours of service, an educational award of \$5,000 is provided that goes toward college tuition. After two years, \$10,000 is provided. In addition, the stipend that the student receives may not count against their other benefits as income.

The high school counselor and college financial aid office should have information about scholarships. The U.S. Department of Labor website <http://careerinfonet.org> also has scholarship information. Local libraries are another good place to look. Youth need to understand that these scholarship applications must be turned in on time.

Another possible way to earn money while in school is to participate in a work-study program. Federal work study provides part-time jobs for both undergraduate and graduate students with financial need. The program encourages work related to the student's course of study. It is available to both full-time and part-time students. More information is available at the school financial aid office.

The National Collaborative on Workforce and Disability for Youth (NCWD/Youth) at <http://www.ncwd-youth.info/> provides a wide range of publications (briefs, fact sheets, guides, reports, tip sheets, and white papers) for youth with disabilities including ones that prepare students for negotiating the college environment.

The U.S. Department of Education offers A Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities at <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>

## Chapter Twelve: Examples of CIL Youth Services and Programs

We have mentioned a few examples of approaches and services, but let's look at some specific CILs in more detail. These centers may provide some ideas of the range of possible youth services and collaborative partners.

### **Lehigh Valley CIL (LVCIL) (<http://www.lvcil.org>)**

LVCIL in Pennsylvania was founded in 1990. Its mission is to empower people with all types of disabilities to achieve independence in an inclusive community. Their active consumer base has grown by 57 percent since youth transition services began in 2008, and now represents the greatest total number of hours worked in the organization. Staffing has grown from 11 people in 2008 to 38 in 2015. Serving youth has also changed and equalized their consumer gender ratio. They serve 35 percent individuals with physical disabilities, 23 percent psychiatric and 16 percent cognitive, including people with autism. Person-centered planning is done at every level.

Lehigh Valley started their program when they were getting phone calls from parents asking for suggestions on what to do with young adults who were just sitting at home after finishing secondary school. The Pennsylvania Developmental Disabilities Council provided a grant to develop a school to life (S2L) program. This program now includes year-round services, seminars, a six-week intensive summer program, and parent meetings and mentoring. They have an advisory board of young adults. They have greatly expanded since inception. Additional youth programs include Real World Lehigh Valley, Road to Graduation, Leadership in Schools Project, Transition Advocacy Project, Career Path Employment Services, LIFE School-based Services, and disability sensitivity education.

They also offer an eight-week employment skills training class with the focus of preparing young adults for competitive employment. Typically, the training is modeled after a job environment. The young adults learn the skills they need to find a job. Two to four assessments are completed based on their person-centered plans. Each person tries out three to four jobs in a competitive setting. Vocational coaches evaluate the individual supports for each young adult to be successful in their chosen field. The skills training and assessments have a fee-for-service. Vocational rehabilitation provides performance-based funding for helping young adults find a job and then stay on the job for a certain number of days.

### **Granite State Independent Living (GSIL) (<http://www.gsil.org/>)**

GSIL in New Hampshire was founded in 1980 and works with about 45 to 50 students, with all disabilities, each year. The majority of students have significant emotional, behavioral, and mental health challenges as well as learning disabilities and attention deficit disorders. The focus of their program is to reengage these students in their education by providing career exploration activities, work experience in the community, and pre-employment skills training. GSIL works with about 100 community partners

that assist with educational and work experiences. Classes take place at GSIL. Students can earn academic credit for the classes that they complete. The program experience is included in every student's IEP and transition plan.

Transition services include both pre-employment and employment skills training. This training typically involves completing applications, practicing interviews, developing resumes and assessing work. GSIL assists with job placements and vocational rehabilitation. All trainees complete a work experience after finishing pre-employment and skills training.

Many students don't know very much about their disability. Often they have never looked at their IEP. GSIL educates students on their disabilities, available accommodations, their IEPs, and whether to disclose their disability to employers.

Another important aspect of youth services is independent living skills training. Public transportation is an issue for many individuals with disabilities, so the Manchester Transit Authority provides transportation training. GSIL has a finance person who works with the local banks and credit unions to educate the students about personal finance. GSIL also offers programs and classes in health, fitness, and nutrition; communication and social skills; personal growth and advocacy.

Advocacy training usually results in major personal growth. When students return to their school, they have a better understanding of what their future career is all about and begin to have a voice in their IEP.

### **The Metropolitan CIL (MCIL) ([www.mcil-mn.org](http://www.mcil-mn.org))**

The MCIL youth transition program assists young adults with disabilities with making a successful transition from high school to post-secondary education, employment, and independent living in the home and community of their choice. Essentially the purpose of youth transition is to ensure that young adults gain the needed skills, knowledge, and interagency relationships to establish their long-range goals for independence after high school. Youth are always in the driver's seat.

MCIL offers five primary areas of youth transition, including assistance with employment, home living, recreation and leisure, post-secondary education, and community participation. Staff members facilitate addressing these five areas in both student IEP planning and family planning with parents and siblings, so that youth have a well-rounded and balanced life when they leave the secondary setting. Planning early makes everything go smoother. Youth participate in person-centered planning meetings to see what they have, where they have been, what their options are, and what needs to be done to get them where they want to go, so that their wants and needs are realistically fulfilled. An online resource on adult benefits helps connect youth to resources. The goal is to put the needed pieces in place for a young adult to accomplish their goals and dreams.

Their IL/VR collaboration project allows MCIL to embed IL specialists in the 12 workforce centers around the metropolitan area of Minneapolis/St. Paul. If it is noted in the intake process that the individual may benefit from some independent living services, they can immediately be matched up with the IL specialist who's embedded with the team. Results have shown a 67 percent success rate in employment outcomes for the individuals who participate in that IL/VR collaboration as opposed to a 46 percent success rate for those that don't. MCIL has a full-time ADA specialist who responds to requests for ADA information and referral, education, training, and technical assistance.

Beginning in 1994, Minnesota CILs received a \$250,000 grant from the Minnesota Department of Education specifically for transition. In State Fiscal Year 1995 – 96, the \$250,000 was included in their core state allocation, which continues today. MCIL doesn't view their transition program as something separate or ancillary. It is wrapped into their overall IL program and viewed as a consistent part and function of their core services. Even though those funds are rolled into those core service dollars, the understanding is that it will be used for youth transition services.

### **Living Independence for Everyone (LIFE) of Mississippi** **([www.lifeofms.com](http://www.lifeofms.com))**

LIFE of Mississippi offers a youth program called Healthy Opportunities for Transition (HOT) with a mission of establishing a strong, responsive system of transition services for Mississippi children with special health care needs and their families. This includes bringing together diverse groups and individuals to build community infrastructure, resulting in successful transition to adult life. HOT provides comprehensive, family-centered, culturally competent transition services. Their primary focus is on health, preparing youth with special health care needs to make successful transitions to adult and community life including adult health care and related services, employment, and independent living.

HOT was originally funded by the Department of Health and Human Services, Health Resources and Services Administration (HRSA) in 2001 as a contract between LIFE and the HRSA grantee in Mississippi (Coalition for Citizens with Disabilities). After that program ended in 2005, the state department of health contracted with LIFE to provide services to young people with disabilities, and still does. This funding is the primary reason why the youth program focuses on health, among other areas.

LIFE obtained funding from the Mississippians against Obesity Foundation to teach an eight week course on health and wellness for people with disabilities. AmeriCorps provided additional funding for the youth program. The University affiliated program through the University of Southern Mississippi is another funding source.

The program objectives include: 1) Mississippi children between the ages of 0 and 21 with special health care needs receive services necessary to make successful transitions from one stage of life to another. 2) Services include peer support, skills training, advocacy, information and referral and other independent living services as



needed. 3) Families of children with special health care needs receive training and on-going support services to help their child confidently transition from a pediatric health care setting to adult health care providers. 4) Health care professionals and service system agencies receive training and support equipping them to facilitate successful transitions for children with special health care needs from pediatric care to adult health care providers.

Transition services include working with consumers and their families to prepare for life changes such as transitioning from middle school to high school, school to employment or from their parents' home to community living. Planning the future after high school involves ensuring that appropriate services are provided while students are still in school. HOT specialists are well trained on IEPs, section 504, IDEA, and other laws and options that affect students with disabilities. They attend IEP meetings as an advocate. A transition clinic for youth from age 14 includes transition services, peer support, advocacy, resources, health care management strategies, and establishing a medical home.

The HOT youth advisory council is very active. They plan and direct annual retreat weekends for youth and parents. The retreat focuses on transitioning from parents' home to the community, veterans, voting, sexuality, health, recreation, and more.

## Chapter Thirteen: Obtaining Program Funding

Your center may find it difficult to provide all of the funding for the services that many young adults with disabilities need with only Parts C or B funding. It is better to have several funding sources. Relying on just one source of usually limited funding may not be the most effective way to sustain or grow youth services or other programs. Increasing income can increase the center's mission.

There are a number of possible funding sources and ways to obtain additional funds. Consider private sector and federal grants, corporate and individual donors, fees-for-service, fundraising, and connecting with local county offices, health departments, and other agencies to supplement funding for youth services. There are many opportunities to support youth transition services and activities, including the following:

- A) City and County Community Development Block Grants (CDBG) – Many cities and counties provide block grants to nonprofits every year on a competitive basis. These are usually housing related and centers can provide accessibility reviews and suggest or complete home modifications with these funds, for example. Check with the city or county administrative offices. More information can be found at [http://portal.hud.gov/hudportal/HUD?src=/program\\_offices/comm\\_planning/communitydevelopment/programs](http://portal.hud.gov/hudportal/HUD?src=/program_offices/comm_planning/communitydevelopment/programs)
- B) State Departments of Human Services or Children and Family Services that receive Title V funding – The U. S. Department of Health and Human Services provides Maternal and Child Health Title V funds to all states. One of their performance measures is to conduct outreach and community living for children and youth with special health care needs. The CIL is well-positioned to provide those services. Talk to that agency and find out if they are meeting their goals and would like to collaborate. The center can assist with outreach, services for children and youth with developmental disabilities, and transition services.
- C) State Legislative Appropriations – Some states provide additional funding for centers every year for youth services, assistive technology, or other purposes. Build relationships with legislators. Invite them to visit the center offices. Provide stories, numbers, and information on the number of people served, center budget needs, and program outcomes. Consider holding a state meeting of youth with a legislative awareness day.
- D) Health and Family Services – Look into the programs offered by local and state health departments, as well as family services. At least one CIL has received funding to include an underserved population of people with disabilities in “healthy relationships and abuse prevention training programs.”

Also check out the state departments of education and rehabilitation as well as local VR offices and schools for potential collaboration.

- E) Fees-for-service – Several CILs around the country have established fee-for-service (FFS) programs with the local VR agency and with school districts. Fees-for-service can help expand a CIL’s capacity as well as provide sustainability. Having contracts with VR and school districts can also confirm the value of services and strengthen the professional role of the CIL as part of the youth transition and employment preparation team in a community. The IL-NET offers extensive training material and resources on establishing and managing FFS within a CIL, including on-demand training videos at <http://www.ilru.org/training/establishing-and-managing-fees-for-service-cils> and <http://www.ilru.org/training/expanding-cil-capacity-through-youth-transition-services-collaborating-with-school>.

The first page includes general training and resources on FFS. The second is specific to vocational rehabilitation and school districts.

- F) Federal funding – The best place to find federal funding opportunities is on the website, [www.grants.gov](http://www.grants.gov). Searches for current Requests for Proposals can be completed by entering keyword, eligibility, agency, category, funding instrument type, or CFDA number. In addition to finding grant opportunities, grant application packages can be downloaded, completed, and submitted.

Sign up for an email subscription to receive notification of grant opportunities. All grant notices can be sent daily, or notices based on eligible applicant, funding type, category (agriculture, arts, community development, education, health, youth, etc.), or agency.

- G) State Developmental Disabilities Council (DDC), Autism Council and others –The DD Council and Autism Council provide small grants for projects that serve people with developmental and other disabilities in some states. Developmental disabilities councils in Pennsylvania, Utah, New York, and other states have funded grass roots projects. State DD councils can be located on the following website: <http://www.nacdd.org>.

- H) Giving Campaigns (i.e. United Way) – Apply for funding through the local United Way office and any other giving campaigns. Look up state locations at: [www.unitedway.org](http://www.unitedway.org). Several CILs have started their youth programs with United Way dollars. Some have sustained portions of their programs with this type of funding.

- I) Local corporations, foundations, service organizations – Meet with potential corporate partners to explore partnerships. Often local corporations, or local branches of corporations, will provide small grants for services or donate materials to a consumer project. Some centers have received funds from their local pharmacy, Walmart, and Home Depot, for example.

Some states have directories of foundations. The Foundation Center lists local resources free of charge. They also send out weekly funding alerts with grant opportunities. Additional information can be found on their website at

[www.foundationcenter.org](http://www.foundationcenter.org). More about the foundation center is also provided under grant tips.

Start by getting to know local funders. Go to events where they are. Attend the activities that they sponsor. Visit their offices and tell them about the center. Get involved in a service club (Rotary, JCs, Lions) to learn about organizations that make grants. Service organizations also may be able to provide volunteers.

- J) University Centers for Excellence in Developmental Disabilities (UCEDD) – There are 67 UCEDD's, located in every U. S. state and territory. All UCEDD's are part of universities or medical centers. They serve as a bridge between the university and the community, bringing together the resources of both to achieve meaningful change. Some CILs partner with their UCEDD on training, research, evaluation, and other projects. The UCEDD may have available funding to help with some of your projects or services. They can also probably help write grants to obtain additional funding.
- K) Fundraising Events – There are many fundraising ideas on the Internet, including Pinterest and Google. There are also a variety of books on Amazon or from other sellers. Partner with local restaurants to see if they will donate a portion of their proceeds. Set up a walk or run with an entry fee. For more ideas, check out [www.fundraising-ideas.org](http://www.fundraising-ideas.org).

Some individuals and organizations have set up donation websites through such websites as [www.gofundme.com](http://www.gofundme.com), [www.crowdrise.com](http://www.crowdrise.com), or [www.indiegogo.com](http://www.indiegogo.com)

- L) Individual Giving – Build relationships with affluent and well-connected community members. Individual donors often account for a large part of annual charitable giving. Ask the center board to identify, cultivate and solicit donors and local philanthropists. Ask them to contribute an amount that they are comfortable with. Individuals may be asked to contribute through telephone solicitation, mail campaigns, special events, matches, etc.

## Chapter Fourteen: Next Steps

The next step is to figure out how to use information from this course to start or expand youth services. Get started by drafting a one to two-page youth program strategy for the center, with active participation by youth in defining the strategy. It is best if this strategy includes a vision or mission statement, goals, objectives, activities, timelines, responsible staff, and evaluation measures. If the center already has youth services, write down how they will be enhanced or improved. Identify what will be accomplished and the steps that will be taken during the next week, month, and six months. Review the draft with other youth and staff for their input and recommendations.

As one of the steps, consider developing and disseminating a survey that asks participants what they would like to see youth services include, which activities they feel are currently missing, and which activities youth with disabilities do not currently have access to. It's easier and saves time for participants if the most common options are already listed with space to write in answers at the end. The survey can fairly quickly be developed, completed, and analyzed online through such programs as Survey Monkey, Qualtrics, and SurveyGizmo.

It's better to start realistically with the youth activities, services, or programs that the center can manage. Start where the comfort level and capabilities are, but always make sure that youth are the driving force.

Hiring young adult staff, and at a minimum, setting up a youth advisory council are excellent ways to obtain their best continued input and ideas. Youth can shadow the center advisory council or board in the beginning to increase their understanding of how councils and boards work. Don't be discouraged if it is difficult to get everyone together. Consider using technology for communicating. Start small, if necessary, and keep building or expanding with youth at the helm.

Youth activities and programs also need to be included in the center's strategic plan, and in both the program plan and budget plan required by the funders. Obtain the commitment of the advisory board, director, managers, and staff. Develop and bring in partners, both in the disability arena and in other areas, such as youth services, employment, education, and recreation. Established partners can help generate enthusiasm, shared commitment and hopefully some resources, too.

The odds are that the way that core services are provided through the center will need to change a bit in order to appeal to youth. Often in the past youth programming was added when there were some left over funds. People learned the hard way that planning is necessary. Conduct strategic planning for youth services/programming, similar to other CIL programs. Transition to post-secondary life is now a core service. Both the board and upper management need to understand the importance of, and provide support to transition services to young adults.

Be thoughtful about what the center wants to accomplish for young adults and make plans accordingly, with meaningful youth guidance. Start by thinking about what it is

that you want to see happen in your CIL and the population you serve. Collaboratively develop a plan with youth to implement those goals, including timelines and staff and/or volunteer responsibilities. There are many factors and questions to consider, including the following.

- What are the demographics of the youth population?
- What are your goals for this year and the next two or three?
- What does your CIL believe creates change?
- Where does the money come from?
- How will the CIL build the funding to support the program?
- What are the projected time frames to launch this program?
- Which services are already being offered in the community?
- What is the current capacity to serve the youth program?
- What knowledge, skills, experience, interest, and level of commitment does current staff bring to developing a youth program?
- How will the program be sustained?

Providing youth services will be an ongoing process. Developing the program and services may be a trial and error process, but stay with it. Remember that not all CILs are the same size, but most likely everyone started at the same place. Conduct thoughtful planning and systematic implementation. Do everything you can to make your program a success so that youth can count on it being available over the long haul.

Remember that if plans do not include people with developmental and cognitive disabilities, there is a good chance that services and activities are not going to be accessible to these populations. Consideration needs to be given to what it will take for people in group homes to participate, so that they can attend. Youth with developmental disabilities may have the greatest need to learn self-determination and independent living skills.

Foster youth services systemically. Public policies that promote youth inclusion are important to consider. The State Plan for Independent Living (SPIL) and the VR state plan need to be inclusive of youth transitioning and youth services.

Think about the center as a workplace. A lot of CILs are small, without extra space. The point of working with youth is full inclusion. Think about where young people hang out. Consider collaborating with a library, community or recreation center, or other local places attractive to youth. Ask them if they will provide some space a few days a week for a few hours, or whatever time is needed for the youth with disabilities to work and have meetings.

Be flexible in your scheduling. Center activities need to fit school schedules. Activities and programs have to be adaptable in terms of fitting with young adults' schedules during the school year and summer.

When youth come in to one center, IL staff asks, “What brought you here and what would you like to accomplish?” Young adults stay in charge of their goals, find resources and drive decision making. The job of staff is to point out the consequences to those decisions, and ensure that youth have a well-rounded selection of options and resources to choose from. It is vital to keep the young person, just like an adult, in the driver's seat to choose those decisions, and to choose their course. They might make a mistake. They might make a bad choice, and that's okay. It's perfectly acceptable. It happens. It's as powerful a teaching tool as anything else.

Developing new youth services can sometimes feel overwhelming. Most centers that offer youth transition services started small and kept it manageable. Move on to the next piece when resources and skills allow. Centers can only do so much with their available staff and funding resources. The program will build and grow on its own if it is planned and executed well, with youth at the helm.

## Chapter Fifteen: Summary

CIL youth services provide transition assistance, leadership opportunities, advocacy, and the chance to participate in community, social, educational, employment, and recreational activities. There are no other organizations that provide these critical self-directed services for youth and young adults with disabilities in the way that CILs can and do. Youth, parents, siblings, center staff, and funders appreciate the beneficial aspects of youth programs.

Even a small center without a grant writer or a public relations person can develop and grow a good youth program. The program might be smaller, but it can still provide worthwhile services. Youth services can have a positive lasting impact for young adults with disabilities, parents, the CIL, and the community.

Independent living is about people of all ages being in charge of their own lives. If a center and staff can hold that philosophy close, it's possible to create and maintain a successful youth program.



## Appendix

Following are key definitions that apply to services for youth in transition from the Final Rule for Independent Living Services and Centers for Independent Living issued October 27, 2016 and effective November 28, 2016.

### Definitions § 1329.4

***IL Core Services Definition for Services to Youth in Transition:*** Services that 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 (20 U.S.C. 1414(d)), and who have completed their secondary education or otherwise left school, to postsecondary life. Individuals who have reached the age of 18 and are still receiving services in accordance with an Individualized Education Program (IEP) under IDEA have not “completed their secondary education.”

***Completed Their Secondary Education:*** means, with respect to the Independent Living Core Services that facilitate the transition of youth who are individuals with significant disabilities in section 7(17)(e)(iii) of the Act, that an eligible youth has received a diploma; has received a certificate of completion for high school or other equivalent document marking the completion of participation in high school; or has exceeded the age of eligibility for services under IDEA.

***Youth with a Significant Disability:*** means an individual with a significant disability who—(1) is not younger than 14 years of age; and (2) is not older than 24 years of age.

***Individual with a Significant Disability:*** 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.