

# **Survey Results and Analysis Youth Participation in Centers for Independent Living**

**August 2009**

## **Background**

Many centers have expressed an interest in adding or enhancing services, supports, and outreach activities to youth and young adults with disabilities (ages 14-22). Youth may face more challenges to achieving self-determination and independent living than adults with disabilities. Because of their age, they are sometimes omitted from the decision-making and policy-setting activities that affect their lives, even in consumer-directed centers for independent living. ILRU conducted a survey in August 2009 titled *Youth Participation in Centers for Independent Living* in order to collect information for planning training and technical assistance activities for CILs that will assist them in outreach and inclusion of youth and young adults at all levels of center services and operations. This report summarizes the results from the 100 respondents who completed the survey.

## **Summary of Survey Results**

A majority of respondents stated that their CIL involves youth and young adults in a broad variety of ways. More than half (66%) have youth transition programs, 62% collaborate on projects or services with community youth groups or organizations, 45% reported that their CIL sponsored youth support groups, and 43% reported youth and young adult participation in systemic advocacy activities such as visits to legislators. When asked what kinds of services CILs provide to assist youth and young adults with disabilities, the overwhelming majority (82%) reported that they provide IL skills training (e.g. budgeting, self-advocacy, home management) and participate in the education/IEP process, 79% provide transition from school, 67% provide support with assistive technology, 62% assist with locating housing, and 56% assist with finding employment.

The data indicated that 73% of respondents work with state vocational rehabilitation agencies in addressing transition issues. When asked to describe how their CIL works with VR, a wide array of responses included collaboration on projects or services with community youth groups, cross-referrals, trainings for CIL and VR staff, developing transition plans, advocating on students' behalf to address physical or attitudinal barriers, and working with VR counselors to locate resources that are not commonly used.

67.7% of respondents stated that they work with local school district special education administrators in transition planning. Again, the examples varied broadly and included electing to have CIL staff present at the ARD to provide support and advocacy, being actively involved in the IEP process to ensure that it is inclusive of all educational factors needed for the success of each student, and teaching IL skills and transition

skills in the school system, working directly with the special education administrators and staff. Other responses included participating in transition advisory councils and career day fairs, and providing education on employment opportunities in the community.

When asked at what age the CIL begins working with youth in the transition process, 61.8% indicated they begin at 14-15 years, 22.5% begin at 16-17 years, and 15.7% begin at 17 years or older. When asked if the CIL has membership in or affiliation with any local or national youth organizations, a majority (72.4%) stated that they do not.

The final question asked the respondents to rank the list of training or technical assistance areas that their staff would be interested in participating in, with results from highest to lowest as follows:

1. Designing a leadership development process for youth and young adults with disabilities;
2. Delivering programs and services to youth and young adults with disabilities;
3. Understanding how to run an effective outcome-based school-to-work or higher education youth transition program;
4. Engaging youth and young adults with disabilities in systems advocacy;
5. Marketing programs and services to youth and young adults with disabilities;
6. Involving youth and young adults with disabilities in design of programs and services;
7. Involving youth and young adults with disabilities in the management and direction of the center; and,
8. Understanding the role of vocational rehabilitation.

Following is a copy of the survey with the results for each question. Identifying information has been removed to maintain confidentiality.

**Question 1: Which of the following ways does your center involve youth and young adults with disabilities (check all that apply)?**

<b>Response</b>	<b>Count</b>	<b>Percent</b>
Youth transition program	66	66.0%
Center collaborates on projects or services with community youth groups or organizations	62	62.0%
Youth support groups	45	45.0%
Participation in systemic advocacy activities (e.g. visits to legislators)	43	43.0%
Youth or young adults with disabilities on staff	31	31.0%
Organized youth mentoring program	28	28.0%
Membership on board of directors	18	18.0%
Participation in the center's strategic planning process	15	15.0%

<b>Response</b>	<b>Count</b>	<b>Percent</b>
Membership on advisory committees	12	12.0%
Membership on board committees	11	11.0%
Membership on an advisory committee specifically addressing youth issues	11	11.0%
Other (please specify)	23	23.0%

**Question 2: With which of the following does your center assist youth and young adults with disabilities (check all that apply)?**

<b>Response</b>	<b>Count</b>	<b>Percent</b>
Education/IEP Process	82	82.0%
Self-advocacy	82	82.0%
IL skills training (e.g. budgeting, self-advocacy, home management)	81	81.0%
Transition from school	79	79.0%
Assistive Technology	67	67.0%
Locating housing	62	62.0%
Employment	56	56.0%
Obtaining health care	43	43.0%
Transition out of institutions	43	43.0%
Other (please specify)	13	13.0%

Other:

Mentoring and support groups. Participates in the Disability Mentoring Program which exposes students and young adults with disabilities to employers and the ins and outs of the working world.
Transportation/mobility training, social/recreation opportunities, development of interpersonal skills, cooking instruction, community service/volunteer activities, interpersonal relationship skills, leadership development, self-esteem enhancement
Personal Attendant Services
Benefits
Referrals to other local community agencies
We are working on forming a "Peer Group" for youth with disabilities. We also have started a website designed by & for the youth to network, post events, find friends & answers.

**Question 3: Does your center work with the state vocational rehabilitation agency(ies) in addressing transition issues?**

Response	Count	Percent
Yes	72	73.0%
No	27	27.0%

**Question 4: If you answered yes to the question above, please describe how your center works with the state vocational rehabilitation agency(ies) in addressing transition issues**

This office provides additional funding for the consumer's initial set up costs [in acquiring a new apt. etc.]
Our center networks with [VR] and its transitional case manager that works with youth. We also attend workshops and seminars that are geared to transition of youth
Collaborate on Transition Partner Committee along with other community agencies.
Funding for our Youth in Transition program comes through [VR] with guidelines established in advance for the program by [VR]
Working with VR counselor to start an all girl mentoring group. Currently working with VR counselor to coordinate visits in the school setting.
We provide computer training in order for transitioning youth to gain employment. We counsel individuals on how to write a resume and how to act and dress for an interview.
Youth Advocate provides training as well as collaboration efforts to improve transition services.
Youth Transition Collaboration meetings, Youth Leadership Forum recruitment
Grant through [VR] which has multiple staff members helping with transitional services at the schools in our area.
We educate students on when they can contact and begin working with VR. In addition, for our transition program, we have invited and had VR counselors come talk about what they can do for youth in transition.
We correlate the IEP plan developed by our youth with the plan developed by the state agency to ensure that the individual receives the services necessary for a successful transition.
Our employment counselors work directly with our state VR and our VR is actively part of our youth leadership program, giving presentations etc.
We get referrals from VR to provide assessments and services to transition-age students. Our Summer Transition Program also visits VR to learn about their services.
Referral and they are also our monitoring agency.

The [VR] organization is our primary funding source. We collaborate...through outreach, referral to / and from our agency, and through coordination of some cases.
Regional Transitional Coalition Providing trainings to VOC Rehab providers
Advocating on the students' behalf to address any physical or attitudinal barriers.
...participated in the CHIRP project piloted by CURRENTS. From this experience, a working relationship has been forged between the center and the transition vocational rehabilitation counselors in the area. The CIL and the TVRCs implement joint projects such as the Transition Connection, make cross referrals, and often administer concurrent consumer cases.
We network and attend ARD and ITP meetings to help transition students after they graduate to see what it is they want to do whether its work or educational needs so that they can become more independent.
We collaborate with [VR] by cross referrals, trainings for staff and [VR] staff.
Work Incentives Planning and Assistance
Being at the table side by side with youth to be sure that their voice is heard/ work with Voc. Rehab counselors to find resources that are not commonly used.
Developing transition plans
Job coaching, testing for other educational opportunities for future, and etc.
We have a grant through our VR system to provide support in the transitioning process and to teach youth self-advocacy.
Through Youth Leadership Program and Also the Youth Employment Readiness Program.
Staff work through [VR] referrals
We have a dual service agreement that works with VR services and the ILC to provide services to consumers 14 to 21 and assisted them and their family with aspects normally not provided by VR services
Looking at employment and also what is needed if they want to continue education.
We work with Voc Rehab on a very limited basis. We have made several contacts trying to seek a working relationship, but to date we have not received referrals
We have an arrangement called Pathways with which we have two [VR] counselors on staff. We work very closely with them to ensure youth eligible for [VR] services obtain services. The relationship also helps to identify youth that are eligible for DD services, as well as those that fall thru the cracks and are not eligible for either but may still require transition assistance.
VR refers youth on their caseloads who need to access community resources and supports to our IL specialists.
[VR] District staff on Youth Advisory Board. [VR] District staff participating with Youth Transition Program presenting employment related information. [VR] involved with outreach for Youth Mentors

They are often, unfortunately, the only source of funds needed for tools, equipment, tuition, etc. for young people transitioning into the community. We will work with them if that unhappy fact compels us to, otherwise, we avoid them. As far as we're concerned, they have always done, and continue to do, a MISERABLE job of helping young people with disabilities.
Our CIL receives referrals from VR to provide IL skills training to youth during summer or after school
...works closely with the local VR agency by working jointly on public presentations to youths and parents regarding transition
We refer young people to [VR], we also work closely with them in assisting young people in planning their future... obtaining employment, going to school, etc
[VR] does little with transition issues but we are available to help when asked.
Referral and advocacy for the consumers interested in career development for future employment or direct employment.
CARF accreditation is mandatory for working with [VR] in this state
We both attend their transitions meeting at school. VR uses our office as a meeting place and will include our staff in meetings
Planning youth activities, outreach to the schools about benefits of IL services
Through a grant via IDEA discretionary funds ILC/School Partnership Program and collaboration and referring students
We received a grant from our state vocational rehabilitation agency to expand our transition program serving youth and young adults with disabilities with a goal of competitive employment.
We make referrals to [VR] and MRDD. Also have a collaborative grant with both agencies.
We collaborate with VR counselors who work with youth. We do fee-for-service work for youth where IL skills are needed to move forward in their [VR] plan.
We use each other as resources as issues we may be able to help each other on a rise
Our...program receives funding from VR. Though we do work with each other, the collaboration could be developed more so that it would have more depth and impact.

**Question 5: Does your center work with local school district special education administrators in transition planning?**

Response	Count	Percent
Yes	67	67.7%
No	32	32.3%

**Question 6: If you answered yes to the question above, please describe how your center works with local school district special education administrators in transition planning.**

We have developed the first of its kind curriculum that conducts group trainings for students.
We serve on a transition team for our county.
We are invited to participate in IEP/Transition plan meetings at local high school.
Parents can elect to have our staff present at the ARD to provide support and advocacy. Networking with Diagnosticians is also part of our strategy
Offer and provide in school IL programs; provide ongoing info on CIL services as well as community services
Involved with the IEP process for many children - some schools are more welcoming than others
We attend IEP trainings with the Dept. of education.
Youth Advocate provides training and assists in IEP process with students, parents and school admin.
We aid families through the IEP process and transition planning falls into this category at times.
We work through the schools to recruit special education students who are graduating from high school. We also utilize this partnership to provide transition planning fairs and Disability Mentoring Day events for students with disabilities.
They visit the center on a quarterly basis for some Independent Living Skills training.
Teachers ask us to provide group sessions to youth in the school. The options are identified by teachers who will use IEPs etc to identify the topic we should use of the sessions.
We provide educational advocacy and with this we attend all transition meetings to advocate for the best placement and future planning.
We work with the school district special education administrators and the youth to ensure that the IEP developed is one that is inclusive of all educational factors needed for the success of each student.
The last two summers we have sent letter to the school counselors to have young disabled people come for a summer mentoring program.
We have an Educational Specialist who goes to different schools in the area and assist deaf students in life skills and transitional planning.
Our center teaches Independent Living Skills and transition skills in the school system, working directly with the special ed administrators and staff. The program also works directly with the area transition advisory councils.

<p>We attend IEPs and are part of a Transition Planning Council where several agencies collaborate in providing transition services and learn about each other. We also educate special education teachers about our Summer Transition Program and receive referrals and letters of recommendation from them.</p>
<p>Transition Coalition for our region.</p>
<p>We have really only begun this relationship with schools. We partnered with one local high school and a [state] Model Transition Program for their 250 youth. We also performed outreach and disability awareness workshops to all high schools and elementary schools in our county.</p>
<p>Transition Coalition Transition Plan Advocacy Joint member of LEA's participation in statewide transition planning</p>
<p>Such interaction has been limited; however, some progress is being made. The REACH youth outreach coordinator has participated in school-sponsored events such as transition fairs, made presentations at life skills and vocational adjustment classrooms, and been present at ARD meetings for individual students.</p>
<p>Center staff meet with CSE chairs and/or directors of special education to provide information on resources in the community. Center staff provides training to school personnel on how to develop person-centered transition goals.</p>
<p>We attended IEP meetings where this work takes place</p>
<p>Participate in teacher conferences, do school presentations, and participate in career day fairs....</p>
<p>We are currently working with two transition councils in [two cities]. We work with youth individually in several school districts to educate them about our services. We also assist with transition planning if requested.</p>
<p>A staff participate and is on the transitional team in each county.</p>
<p>We work with developing transition fairs for youth with and without disabilities. Additionally, our Youth &amp; Family Coordinator assists with training parents and youth on how to build a transition plan using person-centered planning. Training is also available to SPED, and several schools participate in Mentoring Disability Day.</p>
<p>Work with administrators in the IEP process as advocates.</p>
<p>Our Youth and Parent Services Advocate attends IEP planning meetings. We are beginning an outcome based Youth led Transition program in conjunction with an area high school.</p>
<p>Staff outreach to the local schools for students transitioning</p>
<p>I currently work with 5 school districts 4 public and One tribal to assist them with addressing needs and alternative remedies to meet the unique needs of the students so they may maintain their education in the Least Restrictive environment</p>
<p>Looking at providing information to schools in regards to choices in the community and resources. We also collaborate with schools in providing education on employment opportunities in the community.</p>



<p>We have established relationships with local school districts to have our transition specialist actually have an office with office hours at some of the local schools. We work very closely to fill in the cracks that public education does not necessarily fill, such as social skills training. Our transition specialist, of course, also works on the basic transition skills with the students: Resume building and creating, volunteer experiences, interviewing, filling out forms, power point presentations, access to services, etc.</p>
<p>Collaboration through Model Transition Program</p>
<p>we participate on various transition councils and parent/student education workshops</p>
<p>Special Education adms call CIL for assistance with IEPs, also serving on Youth Transition Advisory Board. Assist with outreach and recruitment of participants and mentors.</p>
<p>We have launched an exciting new program, starting last fall, in which we partner with the local school district to provide a variety of supports and services. Space &amp; time prohibit more lengthy discussion here.</p>
<p>Collaboratively with IEP process, transition services, we provide IL skills in high school, also advocacy in whole transition process.</p>
<p>[Our center] serves on and advocates at the local Transition Planning Committee meetings to bring attention to the various activities needed to assist a person with special needs during the transitional phase from secondary education to the choices of further education, employment, housing, etc.</p>
<p>[Our center] has a Transition to Adulthood Program that assists individuals with their transition needs, which sometimes involve attending meetings with school personnel</p>
<p>We often work together when providing services to youth individually.</p>
<p>We work with child study teams, students and families in making sure a proper transition plan is in place. We also teach students their rights so they can take part in their IEPs.</p>
<p>We have participated with the [one] City Schools and the [a] Cooperative Transition Grants.</p>
<p>Attend the IEP meetings and share the 4 core programs vision and mission of the center. Provide them with brochures which includes our location and contact nos.</p>
<p>We actually teach a transition class to Freshmen and Seniors at our local High School. We attend many transition or exit IEP Meetings with youth</p>
<p>We plan an annual youth career camp, assist with ARDs/IEPs</p>
<p>we assist in developing IEPs</p>
<p>however, we have a proposal before a school district to provide holistic transitional services</p>
<p>Through a grant via IDEA discretionary funds ILC/School Partnership Program and offering trainings/workshops</p>

Educational advocates attend IEP and ETR meetings to address students' special education and transition needs.
the students which have been on IEPs the counselors may help to make the transition. Also, one of the things that we try and do with the Disability Mentoring Day is to have colleges attend so that the students can see that it is possible for them to attend college and who they will need to speak to. And that colleges are required to make the necessary accommodations for students with disabilities.
Full-time transition coordinator on staff who attends IEP meetings. Also have Transition grants in which we collaborate with the area schools.
We attend any transitional meetings we are asked to attend. And help the school system's understand the true meaning of participant directed CARE
Our youth staff do attend IEP and ITP meetings.

**Question 7: At what age does your center begin working with youth in the transition process?**

Response	Count	Percent
14-15	55	61.8%
16-17	20	22.5%
17+	14	15.7%

**Question 8: Does your center have membership in or affiliation with any local or national youth organizations?**

Response	Count	Percent
Yes	27	27.6%
No	71	72.4%

**Question 9: If you answered yes to the question above, please identify those local or national youth organizations your center has a membership in or an affiliation with:**

CHADD
AmeriCorps
California Youth Leadership
The National Youth Leadership Network and Arkansas Parent Training and Information Center (PTI).
Youth Coalition Family Matters
ADAPT
PYLN CEC TASH

We assisted a young group of students with disabilities to develop a campus organization for students with disabilities. Our CIL and the [local] University office for students with disabilities plan to develop a program to match students with [center] mentors.
National Youth Leadership Network Wisconsin FACETS (parent and child advocacy) Urban Underground and Running Rebels (Youth Organizations)
Local city and county Youth Bureaus New York State YOUTH POWER! (www.ftnys.org) National Youth Leadership Network (www.nyln.org)
Transition Coalition
National Youth Leadership Network. We are extremely interested in a Youth Leadership Forum for Texas that is truly cross-disability and not targeted to a specific group. We have also used the "Reaching My Own Greatness" curriculum developed by People First, as well as, youth curriculum developed by Access Living in Chicago.
Youth Leadership Forum KS Youth Empowerment Academy
We are a member of the Youth Work Investment Board.
Kansas Youth Empowerment Academy
Self advocates
Missouri Leadership Youth Forum; TASH, MoTASH
Special Olympics
SEEE ( Students for Equal Education and employment) it is a local group with members from 3 different school districts
We have former Michigan Youth Leadership Forum (MYLF) students on staff, and we provide mentors for the annual MYLF program.
transition advisory committees and state transition committee
Kansas Youth Empowerment Academy
Young staff member is a member of the National Youth Leadership Network.
We are the facilitators for the Independent Living Group (Advocacy Group organized since 2001 and going strong. We entertain consumers age 18 and above to be eligible to be members.
APRIL Conference (for youth living in rural areas).
Kansas Youth Empowerment Academy Kansas Disability Mentoring Day National Disability Mentoring Day

**Question 10: Which of the following training or technical assistance areas would your center staff be interested in participating in (please give a rank to all that apply beginning with #1 being your first choice)?**

Rank Item	Rank	Points
Designing a leadership development process for youth and young adults with disabilities	1	471
Delivering programs and services to youth and young adults with disabilities	2	454
Understanding how to run an effective outcome-based school-to-work or higher education youth transition program	3	453
Engaging youth and young adults with disabilities in systems advocacy	4	450
Marketing programs and services to youth and young adults with disabilities	5	351
Involving youth and young adults with disabilities in design of programs and services	6	341
Involving youth and young adults with disabilities in the management and direction of the center	7	237
Understanding the role of vocational rehabilitation	8	225
Other	9	26

**Question 11: If you chose "Other" in the question above, please specify:**

Transition young people from school and out on their own
How to effectively involve the family in the transition process.
Understanding how to build an effective collaboration with school administrators and school districts; development of interactive curriculum that spans the 14/22 age range;
The training/technical assistance areas were picked twice each time to underscore the significance and dire need for training in that area. Unfortunately the survey would not let me submit in that manner.
Training for youth volunteerism
Identifying alternative funding streams allowing vocational rehabilitation services to be sidestepped altogether.
Designing and implementing a peer mentorship program for youth; and designing and implementing a transition program for students transitioning from elementary to middle school