Findings from the 2016 CIL New Core Services Survey

Institutional transition to community-based settings
Diversion from institutional care
Youth transition from school to life after post-secondary education

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Background and Introduction to the New Core Services

- 1. Background and Introduction to the New Core Services
- 2. Presentation of Study and Study Findings from CIL Survey
- 3. Discussion of Implications of Study Findings with Session Participants
- 4. Recommendations for Next Steps with Session Participants

Background and Introduction to the New Core Services

On November 16, 2015, the Administration for Community Living proposed a rule change to section 7(17) of the Rehabilitation Act as part of its implementation of the Workforce Innovation and Opportunity Act (WIOA) (enacted July 22, 2014) that amended the definition of independent living core services provided by Centers for Independent Living (CILs) to include three new core services:

- 1) Facilitate the transition of individuals with significant disabilities from nursing homes and other institutions to home and community-based residences, with requisite supports and services,
- 2) Provide assistance to individuals 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 were eligible for individualized education programs (IEPs) under Section 614(d) of the Individuals with Disabilities Education Act, and who have completed their secondary education or otherwise left school to postsecondary life.

ILRU's Charge from the Administration for Community Living for the Survey

- •The purpose of the 2016 CIL Transition & Diversion Services Survey Study was to gain a better understanding of whether CILs were already providing the three new core services as part of their current work, and if so, to whom and to what extent.
 - The survey was sent out prior to the new WIOA rule going into effect.
- •The survey also collected data on what resources CILs thought would be required to fully implement the three new core services.
- •The aim of obtaining this information was to gain a better understanding of the resources and assistance needs CILs may have with the new WIOA implementation guidelines in effect.

Study Methodology

- This study used an electronic survey delivered through SurveyMonkey.
 - All data collected are confidential.
- •The initial survey sample was CILs with federal funding (N=386).
 - Cleaned and refined sample list based on ACL and IL-NET records.
 - Contact information individually verified; non-verifiable CILs removed from sample list.
- •Invitations to participate sent to CIL executive directors.
 - Of the 386 emails sent, 6% (n=23) bounced back as invalid email addresses.
- •The final survey sample, N=366, includes only those CILs that were verified as being operational and that had active email addresses.

Survey Content

- One survey, three sections, 100 items:
 - Institutional transition to community-based settings,
 - Diversion from institutional care,
 - Youth transition from school to life after post-secondary education.
- •Survey questions:
 - Drawn from prior ILRU IL-NET surveys and modified for this survey.
 - New, specific to this survey.
- Pilot tested the final electronic draft of the survey with experienced independent living specialists and former CIL staff.

Data Collection

- Simmons College fielded the survey and managed data collection.
- •The survey was open and available for CILs to complete for a period of about 8 weeks, from mid-August to early October.
 - First invitations sent in mid-August 2016.
 - A series of reminder emails were sent during this time, with the majority of respondents completing the survey in the first 4 weeks.
- •Respondents were offered the chance to win free admission to an ILRU online training course as an incentive for survey completion.

Survey Response

- Respondents
 - A total of 168 CILs (N=168) responded 46% of the CILs identified as being in active operation.
 - Not all respondents completed the entire survey, likely due to its length.
 - 36% of participants completed the entire survey.
 - Within acceptable norms of response rates from health and professional service providers based on the literature

Survey Respondent Characteristics

Respondents were high-level, experienced and knowledgeable.

- 81% were Executive Directors or CEOs/Presidents of their CIL.
 - More than half (57%) had worked at their CIL 11 years or more.
 - 40% had a graduate degree, another 40% reported a bachelor's degree as their highest level of education.
- Most respondents (84%) indicated they identified as a person with a disability.
- 85% reported having either a lot (40%) or some (45%) knowledge about how to contract with other organizations like managed care organizations or other community-based organizations to provide transition services.
- 56% of respondents said they had seen their CILs budget decrease over the past 3 years.
 - 25% report the budget had stayed about the same over that period of time.

Survey Respondent Characteristics

Respondents represented diverse CILs and mid-sized CILs.

- 74% worked at only one CIL that had one location.
 - 26% at a CIL with multiple regional sites.
- Respondents represented CILs across an array of geographic regions.
 - Over-representation of rural CILs.
- Most CILs (67%) had between 6 and 20 staff members.

Questions about the methodology? Sample/respondents?

Institutional Transition Findings

- 1) A substantial majority of CILs reported that they are already performing transition work.
- •Of the CILs that responded to this survey, 57% reported that this is a regular and 27% said it is an occasional part of the work their CIL already does.
- •Most CILs (82%) reported transitioning less than 3 adults age 18 and older per month and most (68%) indicated that they could not transition more with their current funding.

- 2) Nursing homes, rehabilitation facilities, and hospitals are institutions CILs have the most experience transitioning individuals from.
 - The most common institutions CILs have transitioned adults 18 and older from in the past are nursing homes or long-term care facilities (95%), rehabilitation facilities (51%), and hospitals (47%).
- In regard to current preparation to transition individuals CILs say they are prepared to transition people from:
 - 89% nursing homes or long-term care facilities
 - 66% rehabilitation facilities
 - 56% hospitals
 - 52% intermediate care facilities
 - 43% ICF/MR facilities
 - 39% mental health facilities
 - 30% developmental centers
 - 24% correctional facilities

3) A majority of CILs have a specific institutional transition program or approach.

- 66% of CILs that responded to this survey said their CIL has a specific nursing home or institutional transition program; 34% said their CIL did not.
 - 36% of the CILs reporting a specific program said their CIL developed its own program.
 - 33% said it adopted a fully developed program.
 - 27% said their CIL modified an existing program that was developed somewhere else.
- •Of those that adopted or modified a program, a third (33%) used a program developed by their State, and 28% used a Money Follows the Person program.

4) CILs report offering an extensive range of services as part of their transition work.

- CILs report providing a wide range of services, with high consistency across CILs, including:
 - locating and finding affordable and accessible housing
 - working with family members and institutions to secure transitions
 - assessing individuals for services needs and supports
 - helping individuals to find and access services
 - providing financial assistance for transitions
 - learning or re-learning independence skills
 - making connections with medical providers
 - building social networks
 - other supports and services
- 58% of all CILs in this survey report providing between 21-25 different support services to transitioning individuals.

5) CILs use both person-centered and participant-directed service delivery approaches.

- 71% use participant direction models of service delivery, 63% report using a person-centered model.
 - 48% of CILs responding to this survey use both participant-direction and person-centered models.
 - Only 6% of CILs report using a traditional case management approach.
- 61% of CILs reported having a specific Independent Living (IL) specialist dedicated to transitioning individuals with significant disabilities from institutional to community-based living settings.

6) CILs reported a wide range of organizational partners and collaborators.

- The survey question asked about formal collaborations and partnerships. Respondents reported relatively high rates of partnerships/collaborations compared to what was anticipated, including:
 - 62% Area Agency on Aging
 - 55% State Medicaid agency
 - 55% a nursing home or long-term care facility
 - 50% a housing agency
 - 49% another CIL
 - 49% an Aging and Disability Resource Center

7) CILs report reliance on Rehab Act funding, Money Follows the Person, and state agency contracts to fund transition work.

- 40% of CILs reported that funding for transition work comes from Title VII, Part C of the Rehabilitation Act (funding for CIL operations) and 30% from Title VII, Part B of the Rehabilitation Act (funding for independent living services).
- 36% reported funding for transition from the Money Follows the Person program (which sunsets in 2016)
- 23% reported funding from a state agency other than the state Medicaid agency
- 21% report funding from their state's Medicaid agency.

- 8) Nearly all CILs say they do not have sufficient funding to adequately provide services that transition individuals with significant disabilities from institutions to home and community-based settings.
- 92% of CILs responding to this survey say this is the case.
- Half of CILs (50%) say they would need up to a 30% increase in their CILs budget to adequately provide transition services.

9) A substantial majority of CILs say they have insufficient funding to provide the original 4 core services.

- Most CILs who responded to this survey (83%) receive Title VII, Part C of the Rehabilitation Act funds and 60% receive funds from Title VII, Part B of the Rehabilitation Act.
 - 47% receive both Part B and Part C funds
 - 31% report receiving state funds to support the original 4 core services
- To adequately provide the original 4 core services, 21% of CIL survey respondents said they would need a budget increase of up to 20%.
 - 29% said they would need an increase of between 21-40%
 - 18% said a budget of between 41-75% would be needed
 - 12% said more than a 76% increase would be needed
 - 30% said they didn't know what level of increase their CILs budget would require.

10) A majority of CILs indicated that affordable and accessible housing, access to good public transportation, and cost and availability of community-based service providers are challenges in the region in which they provide services.

- •Of CILs who responded to questions about the context in which services are provided have agreed that finding accessible (97%) and affordable (91%) housing is a challenge.
 - 63% disagreed that there is good public transportation in the region their CIL services for most people with disabilities
 - 90% agreed that community-based services are too expensive for persons who do not qualify for Medicaid
 - 83% disagreed that Medicaid pays for enough community-based service hours to meet people's needs
 - 77% disagreed with the statement that there are enough community-based providers available in their CIL's region to respond to consumer demand
 - 70% agreed that there is a lack of affordable attendant care services in their area
 - 60% of CIL respondents agreed that Medicaid income eligibility criteria are too restrictive, making it hard for people with disabilities to qualify for Medicaid's community-based services
- 81% of CILs responding agreed that social isolation is a problem for persons their CIL assists

Conclusions: Institutional Transition Survey Findings

- 1. A substantial majority of CILs are already performing transition work.
- CILs report that they are not adequately funded to make significant expansion in the scope of their transition services or the number of individuals they can serve.
- 3. CILs report they have ongoing relationships with other community organizations such as AAAs and ADRCs, but additional investigation is needed to determine whether these are business relationships and the extent to which CILs can generate additional income to expand services beyond the limitations of their WIOA funding.
- 4. The community and regional context that CILs provide transition services within has substantial challenges beyond the scope of what CILs can individually address that may influence institutional transition potential and success for low-income and Medicaid-eligible and/or Medicaid insured individuals with disabilities into community settings.

Questions about the institutional transition findings?

Institutional Diversion Findings

- 1) Most CILs (66%) said they do not have a specific process or approach for determining whether or not someone with a disability is at risk for entering an institution.
 - Of those CILs that did report having a specific process or approach (29%), nearly half (48%) said their CIL
 developed its own risk determination process or approach from scratch while 29% said they adopted a
 process or approach fully developed elsewhere and 21% said they modified an existing process or
 approach to meet their own needs.
 - Sources for adopted and modified processes or approaches included state Medicaid agencies, other CILs, other state agencies and Aging and Disability Resource Centers.

2) CILs had strong agreement on what key indicators of being at risk for institutionalization are.

The highest consensus items responding CILs agreed upon included:

- 95% A person self-identifies as being at-risk for institutional placement.
- 93% A medical referral is in process for an institutional placement for a person.
- 92% A person receiving HCBS through Medicaid but is not allocated enough hours to meet their support needs.
- 91% A Medicaid ineligible person needs supports and services but cannot afford to pay for them privately and does not have insurance coverage to pay for them.
- 89% A person with a disabling condition who is experiencing recurring serious health problems.
- 87% A person who needs supports and services is put on a Medicaid waiver's waiting list for HCBS.
- 85% A person who needs IL assistance or services and supports and does not have adequate, affordable, and/or accessible housing.
- While 29% of CIL respondents agreed that all persons with disabilities who need IL assistance or supports or services are at-risk to be institutionalized, 62% said it was not an indicator of risk.

3) A majority of CILs (68%) said that the new core service of providing assistance to individuals with significant disabilities who are at risk of entering institutions so that they can remain in the community is the <u>same</u> type of work their CIL already does.

- 4) CILs reported offering an extensive and wide range of services as part of the assistance provided to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community.
 - Services most universally reported included providing:
 - 99% the original 4 core services
 - 97% information and referrals to HCBS
 - 96% information and assistance about transportation
 - 94% assistance in locating and securing affordable housing
 - 94% in applying for in-home services and supports
 - 89% information and assistance about community-based mental health services and resources
 - CILs also provided services in areas ranging from applying for income benefits (87%) to providing assistance
 in finding health care providers in the community (77%) to helping transitioned individuals make friends and
 build and/or sustain social networks (56%).

5) CILs fund institutional diversion-related services primarily through Rehab Act funds and state program funds.

- Of the CILs responding to this survey, 65% reported using Rehab Act Title VII, Part C funds and 51% reported using Title VII, Part B funds for assisting individuals with significant disabilities who are at risk of entering institutions to remain in the community.
- 47% reported using funds from State agencies, 35% from Money Follows the Person funds, and 27% from other Medicaid funds.
- A small percentage reported using funds from managed care organizations (12%) or the Veteran's Administration (7%).

6) CILs reported partnering and/or collaborating with a range of organizations to provide diversion-related services.

- Organizations included other service providers such as Area Agencies on Aging (52%), other CILs (50%), and Aging and Disability Resource Centers (49%) as well as rehabilitation facilities (36%), hospitals (37%), and developmental disability organizations (35%) among others.
- CILs that report having a lot of knowledge about how to contract with organizations, and CILs
 that say institutional transition is a regular part of their work, tend to report higher
 frequencies of partnerships across the organizations identified in this survey.

7) Most CILs (56%) do not have specific IL specialists dedicated to assisting individuals with significant disabilities who are at risk of entering institutions to remain in the community.

43% of CILs responding to this survey say they do have specific IL specialists dedicated to this
activity. A higher percent of CILs that have the largest staff sizes, 41 full-time paid staff or
more, report having these IL specialists.

- 8) Nearly all respondents (93%) said they do not believe their CIL has sufficient funding to adequately provide this new core service assistance to individuals with significant disabilities who are at risk of entering institutions so that the individuals may remain in the community.
- 32% indicated they would require up to a 20% increase to their current CIL budget, 27% said they would need a 21-30% increase, and the remaining stated they would need more than a 30% budget increase.

9) A majority of CILs indicated that affordable and accessible housing, access to good public transportation, and cost and availability of community-based service providers are challenges in the region in which they provide services. (repeating Institutional Transition slide)

- The vast majority of CILs who responded to questions about the context services are provided in agreed that finding accessible (97%) and affordable (91%) housing is a challenge.
- 63% disagreed that there is good public transportation in the region their CIL services for most people with disabilities.
- 90% agreed that community-based services are too expensive for persons who do not qualify for Medicaid, and 83% disagreed that Medicaid pays for enough community-based service hours to meet people's needs.
- 77% percent disagreed with the statement that there are enough community-based providers available in their CIL's region to respond to consumer demand.
- More than half (60%) of CIL respondents agreed that Medicaid income eligibility criteria are too restrictive, making it hard for people with disabilities to qualify for Medicaid's community-based services.
- A large number (70%) agreed that there is a lack of affordable attendant care services in their area.

Conclusions: Institutional Diversion Survey Findings

- 1. A substantial majority of CILs are already engaged in diversion-related work. Most believe the new core service is no different than the work they already do as part of delivering the 4 original core services. Only a small percentage have specialists working in this area.
- 2. CILs report that they do not have adequate funding to provide the new diversion-related core service to consumers who need assistance.
- 3. CILs report they have ongoing relationships with other community organizations such as AAAs and ADRCs, but additional investigation is needed to determine whether these are business relationships and the extent to which CILs can generate additional income to expand services beyond the limitations of their WIOA funding.
- 4. The community and regional context that CILs provide transition services within has substantial challenges beyond the scope of what CILs can individually address that may influence institutional diversion, ability to live in the community and successful diversion for low-income and Medicaid-eligible and/or Medicaid insured individuals with disabilities in particular.

Youth Transition Survey Findings

1) Less than half of CILs (44%) reported that they currently provide transition services as a regular part of the work their CIL already does for youth who are individuals with significant disabilities, who are eligible for IEPs 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 post-secondary life.

 Of the remaining CILs, 38% said this is an occasional part of the work their CIL already does, 18% said their CIL rarely provides transition services for these youth, and 3% said their CIL never provides these services to these youth.

- 2) Most CILs transition only a few youth with significant disabilities who are eligible for IEPs to post-secondary life per month.
- 47% of respondents reported transitioning 1-3 students per month.
- •15% transitioned 7 or more per month.
- CIL respondents were split on whether they could transition more IEP-eligible youth with significant disabilities per month with their current funding 44% said they could, 47% said they could not, and 10% said they didn't know if they could or not.

- 3) About half of CILs have specific transition programs or approaches for IEP-eligible youth with significant disabilities, while the other half do not—using their existing 4 core services for this work.
- Of CILs with specific programs or approaches to IEP-eligible youth transition work, the majority (62%) reported developing their own programs from scratch, another 23% indicated they modified an existing program, and 8% adopted a fully developed program created elsewhere.
- Just over half (52%) of CILs indicated they have specific independent living specialists dedicated to transitioning youth with significant disabilities who are IEP eligible.

4) CILs reported providing a wide range of services to IEP-eligible youth with significant disabilities transitioning to post-secondary life.

- Services most universally reported included:
 - 92% Assistance with goal setting
 - 91% Independent living skill-building services
 - 91% providing information and assistance or referral about transportation
 - 87% other home- and community-based services
 - 86% Self-advocacy skills
 - 78% Obtaining assistive technology or durable medical equipment
 - 63% Assistance in preparing for/applying for college or training programs
 - 63% Job preparation services
 - 55% Helping transitioned individuals make friends, build social networks
 - 52% Assistance in job search and placement
 - 51% Getting involved in meaningful and productive activities in the community (51%)

- 5) Most CILs (77%) also provide transition services for youth with disabilities who are <u>not</u> IEP eligible who are transitioning to post-secondary life, to youth with IEPs who are still in school (87%), and to youth with disabilities without IEPs who are still in school (76%).
- Most CILs (77%) also say the services they provide for youth not eligible for IEPs who are transitioning to post-secondary life are the same as those they provide to IEP-eligible youth with significant disabilities.
 - Of those who say services are different, they indicate that the focus of support is broader and the services are tailored differently to youth with IEPs.
- Most (77%) CILs indicate that the services they provide to youth with disabilities who are still in school are the same whether they have an IEP or not.
 - CILs that say the services are different cite more extensive funding and teaching of IEP-related advocacy skills for students with IEPs.

- 6) CILs reported partnering most with educational institutions in delivering youth transition services.
- Among the choices provided, CILs more often reported:
 - 71% Partnering with vocational rehabilitation agencies
 - 70% Individual high schools
 - 63% School districts
 - 44% colleges and universities
 - 30% State agencies on developmental disability
 - 22% Rehabilitation facilities

- 7) CILs report that funds for youth transition services come primarily from the Rehab Act or State Vocational Rehabilitation Agencies.
- •Over half of CILs use existing independent living funding from Title VII, Part C (65%) and Title VII, Part B (53%) to provide youth transition services.
- •43% percent use funds from their state vocational rehabilitation agency, and 17% from another state agency.

- 8) Nearly all CIL respondents (90%) said they did not have sufficient funding currently to adequately provide the new core service for youth with significant disabilities who are eligible for IEPs and have completed their secondary education or otherwise left school, to post-secondary life.
- Half of CILs estimated they would need an 11% 30% increase in their current budget in order to adequately provide transition services to youth.

- 9) A majority of CILs indicated that affordable and accessible housing, access to good public transportation, and cost and availability of community-based service providers are challenges in the region in which they provide services as noted earlier.
- •More than half (53%) of CIL respondents said that in the area their CIL serves, there are colleges and universities that offer good support to persons with disabilities, including youth with disabilities.
 - However, only 36% agreed that the level of physical accessibility in their CIL's community is fairly high.

Conclusions: Youth Transition Survey Findings

- 1. Most CILs are currently providing transition services for youth with significant disabilities who are IEP eligible and who are transitioning to post-secondary life, but many only work with a few consumers each month. CILs provide a wide range of services as part of this work.
- 2. CILs report that they do not have enough funding in their current budget to adequately provide the new youth transition-related core service to consumers who need assistance.
- 3. CILs report they have relationships with educational institutions and other community organizations, but additional investigation is needed to determine whether these are business relationships and the extent to which CILs can generate additional income to expand services beyond the limitations of their WIOA funding.
- 4. The community and regional context that CILs provide youth transition services within has substantial challenges beyond the scope of what CILs can individually address that may influence successful postsecondary transitions.

Study Limitations

- •Limitations of the survey include the response rate, which although sufficient within the parameters of social science research as noted earlier, could be stronger.
- •There is also the possibility of response bias in that ACL provides a significant portion of the annual budget to CILs and therefore CIL responses may be more aspirational to some questions rather than actual.

Institutional Transition and Diversion Challenges and Opportunities

Drawing from the summary of findings related to institutional transitions and institutional diversions, the following challenges and opportunities emerge:

- In general, centers (CILs) indicate that they are already engaged in institutional transition and diversion work. While the number of individuals served by each CIL varies, the survey findings suggest that transition and diversion work is fairly universal.
- This universality suggests that the transition and diversion services provided through the national network of centers for independent living (CILs) makes it highly promising that practices (including evidence-based practices) for transition and diversion can be identified and disseminated throughout that network.

Institutional Transition and Diversion Challenges and Opportunities

- A challenge for most CILs appears to be securing enough funding to adequately serve the number of individuals with disabilities who need assistance in transitioning from or avoiding institutional placement.
 - Title VII, Rehabilitation Act (as amended) funds are a principal source of funding for most CILs.
 - Open-ended comments from study respondents include statements describing securing additional funds through contracts as being complex and sometimes prohibitive for some Medicaid-funded programs. (From ILRU's experience conducting training and technical assistance on resource development through its IL-NET and New Community Opportunities Center, there are a number of CILs that have successfully operated Medicaid fee-for-service programs. ILRU has worked with several of these CILs which have been successful in Medicaid-funded programs to train and support other CILs as they initiated similar programs

- Institutional Transition and Diversion Challenges and Opportunities
- •There is no evidence through this survey that large numbers of CILs are involved with contracts with health care entities and managed care funding, although in depth treatment of this was beyond the scope of this initial study. (Through ILRU's training and technical assistance work, ILRU staff have experience with several CILs engaged in managed care and health care payers.)

Institutional Transition and Diversion Challenges and Opportunities

- CILs indicate that they provide a wide range of services and supports as part of their institutional transition and diversion work. The types of services provided closely align with service need and contextual factors CILs strongly agreed put individuals with disabilities at risk for institutionalization.
 (CILs are unique in the disability and aging field in their preexisting mandate and experience to provide a wide range of community supports addressing community integration.)
- The multi-dimensional understanding and approach to providing institutional transition and diversion services offered in CILs affords an opportunity to use CILs as a holistic or comprehensive provider of these services. CILs indicate they are aware of the range of factors that support successful institutional transition and diversion. These range from housing to transportation to access/availability of medical care providers to affordability of personal attendants to re/establishment of social networks and addressing loneliness and isolation. CILs seek to provide services that address these factors.

Institutional Transition and Diversion Challenges and Opportunities

- Most CILs have a modest number of paid employees. This likely makes it difficult to provide a wide range of services to all who need them, raising the importance of collaboration with community partners.
- Although most respondents indicate they have formal collaborative relationships with an extensive number of local community-based partners, the large number of collaborations identified causes some speculation that survey respondents might have provided aspirational responses or might be referring to informal rather than formalized relationship through contracts, MOU's, etc. In future surveys, researchers hope to better understand the degree and nature of community collaborations CILs have and how greater formal collaboration could enhance CIL programs and advance transition and diversion activities.

Youth Transition Challenges and Opportunities

- Most CILs are engaged in transitioning youth with significant disabilities to post-secondary life, but only
 for a few is this a regular part of their work. It's more occasional.
- Most CILs that provide youth transition services, provide the same or similar services to youth with significant disabilities who have an IEP and those who do not have an IEP. This lack of distinction provides an opportunity to develop universal programming that supports youth with significant disabilities transition to post-secondary life. This universality in programming may help overcome discrepancies at local or state levels in IEP authorization and/or provision.
- As is the case for institutional transitions and diversions, CILs indicate a major challenge for providing youth transition services is a lack of funding.

Other ideas?

Recommendations for Next Steps

- In-depth interviews with CIL Executive Directors
- Additional survey with CILs one-year post implementation of the new core services
- Other ideas?

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