

# Centers for Independent Living in the Changing Institutional Transition and Diversion Marketplace

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## Key Findings Report

### Prepared By

**Michelle Putnam**, PhD, Simmons College, Boston, MA

**Brooke Curtis**, BA, ILRU, TIRR Memorial Hermann Research Center, Houston, TX

**Richard Petty**, MBA, ILRU, TIRR Memorial Hermann Research Center, Houston, TX

**Darrell Lynn Jones**, MA, ILRU, TIRR Memorial Hermann Research Center, Houston, TX

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

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For additional information please contact Darrell Jones at [dljones@bcm.edu](mailto:dljones@bcm.edu) or Richard Petty at [rpetty@bcm.edu](mailto:rpetty@bcm.edu)

## Background on the Project

On November 28, 2016, regulations went into effect implementing new core services in Centers for Independent Living (CILs) that 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 post-secondary life. These regulations pertain to section 7(17) of the Rehabilitation Act which was amended as part of the implementation of the Workforce Innovation and Opportunity Act (WIOA), enacted on July 22, 2014. The WIOA implementation rule requires that CILs demonstrate minimum compliance with Section 725 for a wide range of CIL activities including provision of IL core services, efforts to increase the availability of quality community options for IL, and resource development activities to secure other funding sources.

CILs have a long history of transitioning people with disabilities from institutional settings to community-based residences and diverting individuals from institutional placement as part of core service funding through the Rehabilitation Act's Title VII Subchapter B and Subchapter C funds prior to the new regulations. In 2007, the Centers for Medicare & Medicaid Services began competitive awards to states to participate in the Money Follows the Person (MFP) demonstration program. Federal funds were provided to assist states in moving individuals with disabilities from institutional care to home and community-based care. This funding was part of rebalancing Medicaid long-term services and supports (LTSS) related to implementation of the New Freedom Initiative. CILs obtained fee-for-service contracts with their states to provide transition services using MFP funds.

The MFP program ended in 2016; however, states can use the remainder of their funds through 2020. Most states have or are considering adding transition services (some with additional case management) to their waiver programs. This approach generally provides funds for the institutional transition itself but does not necessarily support the entry of professionals or advocates into nursing homes or other institutional settings for the purpose of identifying persons who may be able to transition to the community. At the federal level, there is a pending Senate Bill (S 227) and a House Bill (H 5306) that would extend MFP through the Empowerment Act.

During the same period of time, the number of states that contracted with managed care organizations (MCOs) to administer their Medicaid LTSS programs grew from 16 in 2012 to 39 as of September 2018. Most MCOs adopt a capitated rate from the state to provide services to the target population. Then MCOs have the option to contract with community-based organizations – including CILs – for services including institutional transition. Contracts may be for all facets of transition work or for a portion of the work. MCOs have the option of reimbursing community-based organizations in a number of ways including fee-for-service.

## Project purpose

The shift in funding landscape for institutional transition and diversion services occurred quickly, particularly the growth of Medicaid managed long-term services and supports (MTLSS) and the number of MCOs contracting with states. There are more than 380 CILs across the nation that receive federal funding. It is unclear how CILs have adapted to these funding changes including how they see themselves in this new marketplace, what challenges they face in doing transition and diversion work, how they are funding this work, and what type of training and technical assistance needs are required to help them succeed in a more business-oriented model of service provision.

## Project approach and participants

To answer these questions, informational interviews were conducted with a subset of CILs identified as having a net operating budget above one million dollars in 2014. The ILRU survey team believed CILs above this threshold are likely generating income through sources other than grant funding – and therefore the most likely to contract with states' Medicaid programs or with MCOs in their states. The aim of the survey was for the identified CILs to better explain how Centers in general are negotiating institutional transition and diversion work in the changing marketplace.

The ILRU survey team identified 102 Centers that met the budgetary criterion and email invitations were sent to executive directors of the targeted Centers. The majority of Centers responded to the initial email invitation; however, reminder emails were sent in addition to follow-up phone calls to Centers who did not respond to the initial invitation. Of the 102 CILs invited to participate, 57 were interviewed (N=57), which is a response rate of 56%.

Informational interviews with the 57 CILs were conducted by the principal interviewer, Brooke Curtis, between May 16, 2018 and July 13, 2018 and lasted a duration of 30 to 60 minutes each. A majority of the interview participants were executive directors (47 of the 57 interviews, n = 82%) who in some instances included program staff members to help provide fuller answers to questions. The remaining ten informational interviews were conducted solely with program staff or program directors.

Surveyed CILs represented all regions of the United States with 12 from the West (21%), 13 from the South (23%), 22 from the Midwest (38%) and 10 from the Northeast (18%). Of the CILs represented in this study, 50 centers interviewed (88%) were located in states with Medicaid Managed Care contracts.

CILs were asked who they partnered with to do institutional transition and diversion work, how the work was funded, what they viewed as their strengths in the marketplace, what types of challenges they faced in doing the work, who their competition was, and what type of technical assistance would be useful to sustain and further develop these areas of programming and services.

All of the interviews were recorded, transcribed, and coded with a content analysis approach aimed at identifying similar experiences and practices as well as those that differed. The

information was categorized and compiled to report key findings. From the key findings, promising practices and areas for technical assistance were extracted. In the appendices, selected stories of successful institutional transitions and diversions, in addition to unsuccessful institutional transitions are provided as context to these key findings.

This project compiles information on institutional transition and diversion practices targeted towards adults from conversations with CILs. The project is not a research study to investigate and analyze these practices scientifically. Although the survey team stands behind the approach to information gathering and synthesis, it cannot be determined that findings reflect the entire range of experiences and knowledge of either the invited CILs or all CILs nationally. The discussions with CILs were candid. As such, the report contains aggregated information and does not quote or identify individual CIL responses or practices.

## Project team

The project represents a collaborative effort between Richard Petty, Darrell Lynn Jones, and Brooke Curtis at ILRU at TIRR Memorial Hermann and Michelle Putnam at Simmons College School of Social Work. The project team collectively worked to design the informational interviews, obtain and review the information gathered, and compile this report.

## Summary of Key Findings

1. All CILs developed “partner networks” of community organizations that were critical to their ability to successfully transition and divert individuals from institutions.
2. Partnerships with local services and business were informal relationships, while most of the formal partnerships were with funding entities.
3. CILs noted their independent living philosophy as a distinguishing factor. When compared to other organizations that do transition and diversion work, Centers provide peer-to-peer support for individuals of all disabilities transitioning to the community from various settings.
4. CILs indicated that they provide a long-term commitment of the CIL and its services to individuals who transition from institutions.
5. Several CILs stressed the advantages of their partner network to locate housing and strong business practices as unique strengths to reaching successful outcomes.
6. Overwhelmingly, CILs – regardless of where they were located – identified the lack of affordable, accessible housing as one of the biggest challenges they faced in transitioning individuals from institutions.
7. CILs experienced challenges when working with other entities like nursing homes and personal care and home care service providers.
8. Consumers who experienced additional obstacles added complexities to institutional transition and diversion.
9. Staffing concerns – the amount of staff time for transitions, turnover and burnout, and the need to build staff expertise in a business environment – were challenges experienced by CILs.
10. CILs consistently singled out inadequate funding for institutional transitions as problematic.
11. The ways states structured institutional transitions using Medicaid funding were often problematic for CILs.
12. CILs that worked with MCOs spoke about challenges specific to working within managed care.
13. Most CILs indicated that they conduct community outreach for their institutional transition services through traditional venues and channels and do not directly market these services to funders.
14. Despite being split on funders’ awareness of their value, CILs often indicated that they were the only, or one of the very few, organizations doing institutional transition work in their area.
15. CILs are funding transition and diversion work through a patchwork of grants; Rehabilitation Act Title VII funds; contracts with state, county, and city governments; donations; fundraisers; and contracts with health care insurers and MCOs. However, funding usually does not cover all aspects of the work.

16. Lack of funder interest outside of the state's Medicaid program and MCOs was noted as a challenge for CILs in obtaining supplemental funding.
17. CILs in states that are still running a federally-funded MFP program relied heavily on those funds for transitions.
18. In most cases, CILs that were doing a sizeable number of institutional transitions annually had Medicaid contracts or contracts with MCOs.
19. Most CILs with an MCO contract said they had actively reached out to the state or the MCO to develop and secure the contract.
20. Some CILs desired the opportunity to work with managed care and health care companies, but indicated it was not possible based on state level policies, the way MCOs structured their own work, or other factors.
21. CILs that had contracts with MCOs were contracted to do a range of work.
22. Most CILs indicated that contracts did not change the services provided or the assessment of outcomes.
23. Nearly all of the CILs that had contracts indicated that they did more transition work, but did not financially profit from institutional transition work. For most, it was budget neutral. For others, contracts led to a reduction in revenue.
24. Some CILs told us that MCO funding did not cover the full transition cost or provide full reimbursement for CIL services.
25. Both CILs with and without Medicaid or MCO contracts often sought additional funds for institutional transitions from other sources or used Title VII funds.
26. CILs with MCO contracts had mixed views on them as partnering organizations.
27. CILs expressed concerns of needing technical assistance to secure funding and to work with health insurance companies and MCOs.
28. Many CILs are interested in receiving additional training for transitions and diversions work.

## CILs and their Partner Networks for Institutional Transition and Diversion Work

CILs spoke about the role organizational partners played in making the transition not just feasible but successful. CILs described how they utilized partners for various aspects of transitions and diversions, and how partners reached out to Centers when a person at-risk of institutionalization was identified. It is important to understand the way that CILs work with other community-based organizations for institutional transition and diversions work before describing their engagement in the work itself. The key findings in this area are the following:

### 1) All CILs developed “partner networks” of community organizations that were critical to their ability to successfully transition and divert individuals from institutions.

CILs explained their success in transitioning and providing support to individuals in the community as a team effort with community partners, which highlighted how CILs are embedded in their communities. In some instances, partner networks were extensive. While in others they were a few organizations. Most partner networks were cultivated over several decades in local communities. Others were strategically formed as information sharing groups or advocacy coalitions – some dating back to the start of the Money Follows the Person demonstration or Aging and Disability Resource Centers in their states. Some CILs joined existing local networks – for example long-term care coalitions. Partners and partner networks were supported and sustained with regular meetings and presentations to partner agencies, but also through joint trainings, co-location of employees, and other mechanisms.

CILs drew on these partner networks as needed to help individual transition consumers – indicating that no two transitions were exactly alike, as in their consumer-driven model there were many choices and options for consumers. Table 1 includes a compiled list of the partners CILs reported as being in their networks. Where possible, the name of the organization or agency was included. There is potential for overlap in the type of agencies since organization names needed to match exactly to be aggregated. These findings align with a survey completed in 2016 by ILRU where CILs identified partner organizations for transition and diversion services from a provided list of 57 types of organizations. The organizations identified in Table 1 nearly matches the organization types identified in the 2016 survey.

Table 1. Organizations CILs Partner with for Institutional Transition and Diversion Work

<ul style="list-style-type: none"> <li>• ADRCs</li> <li>• Adult protective services</li> <li>• American Red Cross</li> <li>• Area agencies on aging</li> <li>• Assisted living facilities</li> <li>• Assistive technology providers</li> <li>• Banks</li> <li>• Builders and construction companies</li> <li>• Catholic Charities</li> </ul>	<ul style="list-style-type: none"> <li>• Lumberyards</li> <li>• Managed care ombudsman</li> <li>• Medical alert company</li> <li>• Mental health agencies &amp; providers</li> <li>• Moving companies</li> <li>• Neighborhood community assistance organizations</li> <li>• Nursing home ombudsman</li> <li>• Other CILs</li> </ul>
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<ul style="list-style-type: none"> <li>• Chambers of Commerce</li> <li>• Children’s rehabilitation hospitals</li> <li>• Churches</li> <li>• City agencies</li> <li>• Community development agencies</li> <li>• Clothing companies with customized designs for people with disabilities</li> <li>• Colleges and universities</li> <li>• Community food banks and agencies</li> <li>• County government</li> <li>• County intellectual/developmental disability agencies</li> <li>• Disability service providers</li> <li>• Disabled American Veterans</li> <li>• Employment &amp;/or job training organizations</li> <li>• Domestic violence shelters</li> <li>• Durable medical equipment providers</li> <li>• Eagle Scouts</li> <li>• Emergency services including fire and rescue</li> <li>• Foster care/family agencies</li> <li>• Franciscan Sisters</li> <li>• Furniture stores</li> <li>• Grocery stores</li> <li>• Habitat for Humanity</li> <li>• Health care clinics</li> <li>• Health care professionals &amp; provider coalitions</li> <li>• Home care agencies</li> <li>• Home delivered meals agencies</li> <li>• Homeless agencies</li> <li>• Homeless shelters</li> <li>• Hospitals</li> <li>• Legal aid agencies</li> <li>• Local and county housing agencies</li> <li>• Long-term care councils</li> </ul>	<ul style="list-style-type: none"> <li>• PACE programs</li> <li>• Paramedic companies</li> <li>• Personal attendant care providers</li> <li>• Pharmacies</li> <li>• Poverty action organizations</li> <li>• Public schools</li> <li>• Ramp-building companies</li> <li>• Rehabilitation hospitals</li> <li>• Salvation Army</li> <li>• Self-advocates association</li> <li>• Senior centers</li> <li>• Senior communities</li> <li>• Sheriff’s office</li> <li>• St. Vincent DePaul</li> <li>• State Department of Children and Families</li> <li>• State Department of Health</li> <li>• State Department of Mental Health</li> <li>• State Department of Public Health</li> <li>• State Department of Social Services</li> <li>• State Department on Aging &amp; Disabilities</li> <li>• State housing agencies</li> <li>• State low-interest loan programs</li> <li>• State Medicaid agencies</li> <li>• Support groups</li> <li>• Technology companies</li> <li>• Transportation agencies</li> <li>• United Cerebral Palsy Association</li> <li>• United Way</li> <li>• Veteran’s Administration</li> <li>• Vocational Rehabilitation Departments</li> <li>• Volunteer providing agencies</li> <li>• Volunteers of America</li> <li>• Other aging-related organizations</li> <li>• Other charitable foundations</li> </ul>
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CILs stressed the critical role of partners in navigating the complexity of transitions and diversions. Transitions often require many months of work pre-transition to secure housing, services and supports, income supports, health care providers, and other resources. They also

require intensive on-the-ground or in-the-field work to make connections and advocate when needed. To help sustain community living, CILs described providing many months of post-transition follow up to ensure that the consumer is healthy, has a functioning social network, and is achieving their independent living goals. Partners helped with a wide range of things – from alerting CILs to affordable housing openings to donating lumber to building ramps to furnishing homes.

Below is a story shared during the interview that highlights how partner networks are used. This story has been edited to remove any identifying information.

*We recently transitioned an 83-year-old male veteran from a state hospital. He'd been there for about four years and had some cognitive impairment and mobility challenges. He's a wheelchair user. We got him connected with the V.A. to provide some support and we coordinated his case management during the process of his moving into the community. His housing preference was to move to City A. He wanted to be on the first level of a house and preferred to live by himself. Of course, we needed low rent so in order to make that happen we went to our local landlord association meeting, which we go to regularly. We presented what we were looking for, we told them that we will make sure he has a deposit, we'll make sure that during his first six to eight weeks he's got community and medical support and that everything will be set up right. We coordinated all of the services. We also used a veteran's group – Disabled American Veterans – who had a guy who works on wheelchairs and medical equipment so we got a hold of him and said "OK what do you have around in terms of grab bars and those sorts of things?" We got those installed with the help of the husband of a staff person. After he moved into the community, the man ran into some issues with his ramp so we called the local United Way who coordinates our local ramp program and got him a new ramp. Those are the ways we typically use our partners.*

## **2) Partnerships with local services and business were informal relationships, while most of the formal partnership were with funding entities.**

For most CILs, these networks are informal and do not involve memorandums of understanding (MOUs) or legal contracts. Some CILs did have contracts with partners to carry out institutional transition and/or diversion work with state Medicaid agencies, managed care organizations (MCOs), or other organizations that fund institutional transition and/or diversion work. When there was an MOU it was usually used to link the CIL to other service providers to share client information or facilitate referrals. Only one CIL mentioned using MOUs as a tool to forge new relationships and prepare for future funding opportunities where MOUs would need to be in place.

Additionally, most formal partnerships were with funding entities that were described by many as part of the partner network. This included state agencies that distribute federal and

state funds – including Medicaid funds as well as county and city governments, and private grant making organizations. Others did not refer to funders as partners.

## **CIL Involvement in Institutional Transition & Diversions—Strengths and Challenges**

CILs were asked about the institutional transition and diversion work they do and to identify their strengths in the marketplace and their greatest challenges. Key findings in these areas are presented below.

### **Strengths in the Marketplace**

CILs identified their strengths in their local and/or regional marketplaces differently based on how transition work was structured and paid for by public funders in their states. However, the majority of CILs indicated their commitment to the independent living philosophy and their ability to provide a wide range of services and supports – themselves and often through the help of their partner network – made them valuable as an institutional transition service provider. Additionally, CILs noted that their knowledge about transition work and their long-term experience of working with persons with a wide range of disabilities helped to distinguish them from other organizations doing institutional transition work. These and other strengths are further outlined below and listed in Table 2. Below are the key findings:

#### **3) CILs noted their independent living philosophy as a distinguishing factor. When compared to other organizations that do transition and diversion work, Centers provide peer-to-peer support for individuals of all disabilities transitioning to the community from various settings.**

Being consumer-driven was viewed as essential to facilitating successful transitions and supporting diversion. CILs highlighted that their staff included people with disabilities who serve as examples of independent living – particularly to individuals who have lived in nursing homes or rehabilitation hospitals for some time. They indicated that helping a person with a disability believe living in the community was possible was a vital part of the initial transition or diversion process. After relocating, peer support was crucial for aspects like learning to negotiate community living, rebuilding social networks, engaging in work, and other activities.

From first-hand experience with transitions and years of expertise, CILs spoke about knowing how to navigate various systems and being connected in the community. They have experience working through a transition/relocation plan and helping people return to and stay in the community. Some told us that they were well-known at the local and state, and even national level for their work.

The strengths of peer-to-peer support and expertise aided CILs in transitioning individuals from various settings including nursing homes, assisted living facilities, hospitals, and rehabilitation hospitals into community settings. CILs also partnered with domestic violence shelters, homeless shelters, and natural disaster emergency shelters to support individuals

with disabilities who were at risk of being institutionalized as they had medical, personal, or disability-related needs the shelters could not assist with. CILs worked with individuals with disabilities leaving incarceration and/or who had criminal records. CILs mentioned working with individuals in low-income but not accessible housing – to avoid institutionalization.

Some CILs highlighted certain settings more than others – for example natural disasters related to fire, floods, and hurricanes happen more often in certain areas of the country than others. Funding sources also seemed to influence the types of transitions CILs conducted more often. For some CILs, Title VII funds comprised a very small percentage of their overall budget (less than 5%) so they had limited discretionary funds to support transition work compared to transition work paid for by state Medicaid funds if contracted for these services.

**4) CILs indicated that they provide a long-term commitment of the CIL and its services to individuals who transition from institutions.**

This was viewed as different from other service providers who may follow up post-transition. Many CILs stated that once they began working with an individual, they considered that person a member of the CIL and someone they would continually connect with through program and informational channels. CILs described an assortment of services offered to help the person remain in the community. CILs specifically noted peer support, personal attendant services, independent living training, assistive technology programs, home modification programs, and programs that facilitated socialization and friendship-making as being important for providing holistic support to individuals relocating to the community and those who needed support to stay in the community.

Additionally, some CILs offered unique resources for consumers including fitness centers within the CILs, assistive technology libraries, legally-trained staff, accessible housing provided by the CIL through a subsidiary, an independent living skill training center based in a CIL-owned home, and a CIL-owned trailer to help people move. Information on the full program or service offerings of each CIL were not collected, so there are likely many more unique resources that could be identified as assets for transition and diversion work.

**5) Several CILs stressed the advantages of their partner network to locate housing and strong business practices as unique strengths to reaching successful outcomes.**

***Locating Housing***

Locating accessible, affordable housing through leads in their local communities was a strength most CILs identified. Partners included landlords, local apartment complexes, community-based housing agencies, and other partners. Several CILs shared that local housing providers regularly checked with the CIL when an accessible, affordable housing unit became available. Some CILs worked with banks and public agencies with low-interest loan programs to help individuals obtain financing for housing costs including home modifications and assistive technology. CILs indicated that when a home – apartment or house – was not accessible, they used their own resources or worked with partners in their networks to improve accessibility for individuals.

## *Business Practices*

Many CILs noted their focus on improving health and quality of life outcomes as indicators of success as opposed to viewing success as completing a transition and maintaining community living. One CIL spoke about focusing on customer service and customer appreciation. Another spoke about creating a stronger organizational infrastructure to deliver high-quality service. Only a small number of the CILs framed marketplace strengths in this way. However, many of the CILs that did not mention this as a strength expressed the need to move in this direction.

Table 2. Summary of CILs Key Strengths in Institutional Transition & Diversion Work

<ul style="list-style-type: none"><li>• Ability to relocate individuals from a variety of institutional settings</li><li>• Ability to work with people with any type of disability</li><li>• Work framed within independent living philosophy using consumer-driven approach</li><li>• Long-term experience doing transition and diversion work</li></ul>	<ul style="list-style-type: none"><li>• Peer-to-peer approach offers authenticity in helping consumers</li><li>• Provide a long-term commitment to consumers</li><li>• Offer a wide range of services and programs, some unique services</li><li>• Ability to find affordable housing and make it accessible</li><li>• Ability to obtain successful outcomes for consumers</li></ul>
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## Challenges in the Marketplace

CILs identified a wide range of challenges for doing institutional transition and diversion work. Some of these challenges were specific to a region or state, such as the way a state structured the transition program and organizations contracted for work or the culture of the nursing home industry in the state. The identified challenges are categorized into community-level, organizational-level, and funding and contract challenges. Key findings are outlined below and listed in Table 3.

### Community-level challenges

**6) Overwhelmingly, CILs – regardless of where they were located – identified the lack of affordable, accessible housing as one of the biggest challenges they faced in transitioning individuals from institutions.**

CILs in towns with populations of less than 1,000 people spoke as passionately about the need for more affordable housing as did CILs in cities with millions of residents. Some CILs expressed less concern with accessibility of housing than housing costs themselves, indicating they have the resources to make home modifications if they find rental apartments or homes. Most CILs spoke about transitioning individuals who no longer had a home and had very low income or no income and the dependency created on locating affordable housing in expensive housing markets with low supply. Some CILs noted that affordable housing often meant poor quality housing or housing located in remote areas where safety and the lack of access to transportation were greater concerns. They noted that individuals

with disabilities located in areas lacking transportation options were less able to engage in the community and less able to attract and retain personal care attendants who relied on public transportation. CILs also noted that lack of accessible transportation can impact the ability of CIL employees to reach consumers for in-person work as well.

**7) CILs experienced challenges when working with other entities like nursing homes and personal care and home care service providers.**

CILs in some states told us that working with nursing homes and against norms of institutionalization remained a challenge for institutional transition work. CILs gave these examples: state and local political cultures that do not support community-based living for persons with disabilities and provide minimal funds in the state budget for transitions; nursing homes and assisted living facilities that want to keep residents from leaving and do not want CILs to speak with individuals; and HCBS service providers who do not believe that individuals are capable of living in the community.

CILs covering rural areas spoke about the limited available workforce and the few choices individuals had for service providers resulting in difficulty supporting individuals relocating to the community and individuals attempting to stay in the community. CILs in suburban and urban areas also spoke about workforce shortages and less about service provider shortages.

**8) Consumers who experienced additional obstacles added complexities to institutional transition and diversion.**

Several CILs mentioned the difficulty of finding housing for individuals with a criminal record. Other CILs told us about consumers with substance use disorders that resulted in unsuccessful transitions or affected the CIL's ability to work with the individual. A few CILs described situations where the individual had no family or other social network to connect to after returning to the community. At least one CIL mentioned access to mental health services as a central challenge for successfully transitioning some consumers. Additionally, some CILs discussed the challenges of working in areas with a strong local culture that distrusts outsiders. This led to staff spending more time to build relationships with consumers and local organizations. All of these situations were noted by CILs as adding complexity and often additional time to the transition and diversion work.

**Organizational-level challenges**

**9) Staffing concerns – the amount of staff time for transitions, turnover and burnout, and the need to build staff expertise in a business environment – were primarily challenges experienced by CILs.**

CILs spoke at length about institutional transition work being time intensive. CILs mentioned the length of time between the decision to relocate to actually moving into a community-based home could take months and even years, and often depended on the availability of resources like affordable housing, Medicaid HCBS waitlists, speed of response by service and support providers, and other factors. One CIL told us that on average their staff spent 200 hours on each transition case. Another CIL with a large coverage area described the amount of travel time required to meet with consumers – in one case it was several hours one way. Many CILs indicated the lack of staffing for transition work due to limitations of funding to



cover staff time. These factors can lead to staff burnout and turnover, which is problematic for keeping a transition on track. Additional concerns of retaining highly trained independent living staff were associated with low pay. Many CILs said the shift from a grants-based model to a business model would be a substantial adjustment for staff members. Reasons for this varied but included staff not having the expertise required to manage the contracts or negotiate the contract requirements, reluctance to mixing the independent living philosophy and the business model of operations, and staff resistance to change. They also spoke about the need to improve internal business operations in order to better manage contracts and adequately and accurately document transition and diversion services to demonstrate progress and outcomes.

## **Funding and contracting challenges**

### **10) CILs consistently singled out inadequate funding for institutional transitions as problematic.**

CILs that mainly used Rehabilitation Act Title VII Part B and Part C funds cited both the lack of funding to hire additional staff for the time-consuming work of transition and the lack of funding – through state Medicaid programs or Title VII funds – to pay for the items a transitioning person needs when establishing community living. CILs using MFP funds for transitions usually indicated the funds for the individual transition were adequate but did not pay for staff time, which limited the number of transitions due to staff availability. CILs with MCO and health insurer contracts spoke less about funding shortages and more on how funding only covered a portion of the transition work.

### **11) CILs indicated that the way states structured institutional transitions using Medicaid funding was often problematic for CILs.**

Several CILs told us that waitlists for their state’s Medicaid HCBS program were long and slowed down the pace of institutional transitions. Other CILs indicated that they were not eligible to contract for transition services due to funds being channeled through state departments or other community-based organizations. A few CILs spoke about bureaucratic red tape that surrounded how transitions are approved and processed through Medicaid. They noted the need to have the service and support program guidelines align, so community relocation services and supports fall into place for a transition. Others told us that city and state agency silos made it difficult to pool funds across programs to support institutional transitions. Finally, some states brought transition work in-house with their own case managers so contract funds were not available to CILs.

### **12) CILs that worked with MCOs spoke about challenges specific to working within managed care.**

Several CILs noted MCOs do not understand the complexity of institutional transitions. One CIL expressed working with MCO case coordinators who are not local and coordinators with large caseloads, which is more difficult than previous experience of working with the local nursing home social worker. Other CILs stated that MCOs do not fully fund independent living needs once an individual is transitioned, which can influence whether the transition is successful or not. A CIL in a state with managed care explained that once a consumer returns to the nursing home after being transitioned, the consumer converts from the MCO to the

regular Medicaid program, so they felt the MCO had little motivation to ensure the transition was successful.

Some CILs noted interest in growing their institutional diversion work to market to MCOs and other funders who are seeking ways to prevent institutionalization and that the traditional services CILs provide – including peer-mentoring and support, home modifications and assistive technology, health promotion and fitness programs, independent living skill training and other services – are in increasing demand.

A few CILs indicated a lack of interest in working with Medicaid managed care and were continuing to seek additional funding, which was challenging. One CIL indicated that their state was requiring credentialing of transition counselors, which they saw as an unnecessary requirement because of their expertise and the federal mandate requiring them to do the work. Other CILs were interested in growing funding to support transitions and diversions for people who are not insured by Medicaid or enrolled in managed care as another market for their services.

Table 3. Summary of CILs Key Challenges in Institutional Transition & Diversion Work

**Community-level challenges:**

- Shortage of affordable housing
- Lack of accessible transportation near affordable housing
- Workforce shortages in personal and home care
- Community options for persons with criminal records, substance use disorders or mental health needs
- Local cultural context including pro-nursing home culture

**Organizational-level challenges:**

- Time-intensive work for staff, often not funded by external payer
- Staff-turnover and recruitment
- Need to increase staff expertise in business-type model environment
- Need to improve internal communication, reduce silos

**Funding and contracting challenges:**

- Inadequate funding for institutional transitions
- State structure for Medicaid and managed care program limits CILs contracting ability
- State waitlists for Medicaid HCBS
- Timely coordination of funding inhibited by state agency silos
- MCOs not adequately staffed or organized for complexity of transition work
- MCOs not adequately incentivized to do transitions
- Obtaining funds (or supplemental funds) for transitions
- Facilitating growth of contracts for diversion work



## Outreach and Marketplace Competition

CILs were asked about their marketing efforts for institutional transition and diversion services including how their marketing strategies changed over the last five years. CILs were also asked whether they believed funders were aware of their strengths in this area of work and to identify competition in their market. The following are key findings in this area.

### **13) Most CILs indicated that they conduct community outreach for their institutional transition services through traditional venues and channels, and do not directly market these services to funders.**

All CILs mentioned promoting their independent living services – including institutional transition services – in their communities. A range of outreach strategies were identified including distribution of printed materials, media advertising, presentations at community meetings, disability specific and general community events, social media, presentations at nursing homes, through their partner networks, and through word of mouth.

Some CILs reported targeting health care insurance companies, MCOs, and state agencies through direct meetings, trainings for case managers, advisory board participation, and networking activities with key personnel. Other CILs spoke about giving presentations at hospitals, nursing homes, and other institutions as a way of becoming vendors for transition services. However, several CILs stated that they do not conduct outreach for their transition and diversion services outside of general brochures and website information because they do not have enough staff to meet the transition requests that might be generated.

However, many CILs mentioned that the level of complexity and sophistication of their outreach had increased within the last five years. Nearly all CILs mentioned the importance of engaging social media tools for marketing their services, programs, and events. Some CILs re-branded with a changed tagline, logo, or more streamlined materials that better explained their CIL and its services. In general, these CILs were aiming to reach a broader audience.

A few CILs were refining their marketing materials and marketing efforts to target non-traditional partners – like health insurance companies and MCOs – emphasizing their ability to meet client goals, obtain outcomes through transition and diversion work such as better health, employment, and less dependency on public funds. At least one CIL spoke about positioning the CIL as value added, encouraging health insurers to see their services as additions to the services an MCO care coordinator provides to help transition or diversion be more effective.

### **14) Despite being split on funders' awareness of their value, CILs often indicated that they were the only, or one of the very few, organizations doing institutional transition work in their area.**

This was particularly the case for rural areas. When CILs reported having competition, it was often from the Area Agency on Aging or in some cases MCOs. For some CILs, MCOs offered substantial competition. Other CILs noted there was plenty of transition work, so competition was low in their regions. At least one CIL noted their state having a fairly strong

institutional diversion approach. Therefore, the amount of institutional transition work had declined over the past few years. In contrast, a few CILs indicated a strong nursing home industry and a pro-institutionalization culture, which remained their stiffest competition.

## CIL Funding Sources and Challenges for Diversion and Transition

CILs reported funding transition and diversion work and the limited nature of funding was a common theme. CILs spoke about difficulty in obtaining funding, but also about the challenges of working in states with reduced Medicaid funding, the difficulty of working with one funding stream to pay for staff time for transition work and another to pay for the transition itself, shifting funding formulas in states moving from MFP to MCOs, and how funds are stretched thin for transition and diversion work. The key findings on funding sources and challenges are outlined below.

**15) CILs are funding transition and diversion work through a patchwork of grants; Rehabilitation Act Title VII funds; contracts with state, county, and city governments; donations; fundraisers; and contracts with health care insurers and MCOs. However, funding usually does not cover all aspects of the work.**

The majority of CILs use their Rehabilitation Act Title VII Subchapter B and Subchapter C funds to pay for at least some portion of transition and diversion work, but indicated the funds were fairly modest and often did not adequately fund transition work. Some CILs reported that Title VII funds made up less than 5% of their budgets. For others it was a larger share, but the funds were used to cover a range of CIL services, not just transitions. These funds were often used to pay for staff time, which is noted as being a significant cost per person for transitions.

Many CILs had contracts with their state's Medicaid agency, in some cases through the MFP program and in other cases through other state agencies. Medicaid contracts were noted as more fully covering consumer transition costs but did not pay staff costs, which were mainly covered by Title VII funds. CILs working with state Medicaid programs including MFP programs and other state agencies cited funding cuts and lowered reimbursement rates as impacting transition work. A few CILs noted that reduced Medicaid funding increased the need to be selective about who is transitioned as it may not be possible to obtain the full amount of HCBS required for persons needing high levels of assistance. Several CILs said this created a conflict for them as their mission is to support independent living, and the core services require transition and diversion work.

Some CILs had contracts with MCOs or health insurers. CILs with state or MCO contracts reported that most of their funding for transition work came through these sources. CILs with MCO contracts often did not handle the relocation itself but were contracted for specific services like peer-support – which was more financially feasible for some as these contracts paid for staff time. CILs reported obtaining grants from a wide range of private foundations as well as public agencies. CILs regularly held fundraisers to support transition and diversion work. One CIL indicated drawing funds from an endowment. A few CILs told us they used income from a fee-for-service program to fund their transition work.

**16) Lack of funder interest outside of the state’s Medicaid program and MCOs was noted as a challenge for CILs in obtaining supplemental funding.**

CILs expressed that while there are funding opportunities from local foundations or city and county agencies, there is substantial competition among community organizations for funding. Several CILs indicated experiencing funding priorities from foundations, which may not include people with disabilities. One CIL noted the number of homeless people in the area was viewed as such a significant issue; therefore, funding people who have a place to stay – even if it is a nursing home – to move into different housing was a lesser priority than finding homeless people housing.

## **CILs and Contracting with Funders for Transition and Diversion Work**

For contracting with external payers, most CILs had MFP contracts with their state’s Medicaid program. Some mentioned contracts they had with other state, county or city agencies including vocational rehabilitation, housing, community development, area agencies on aging, Aging and Disability Resource Centers, and others. A few spoke about contracts with MCOs, other health insurers, or health care institutions including rehabilitation hospitals and general hospitals. This section focuses on findings related to state Medicaid agencies, health insurers, and MCOs as these external payers were most often cited as funding institutional transition work. Key findings are presented below.

### **CIL Medicaid and Managed Care Contracts**

**17) CILs in states that are still running a federally-funded MFP program relied heavily on those funds for transitions.**

Some states were set to move to Medicaid managed care in 2019 or were in the process of that change. Many of these CILs were uncertain about managed care and how it would affect them. Some were actively exploring relationships with MCOs, while others were waiting for guidance from the state.

**18) In most cases, CILs that were doing a sizeable number of institutional transitions annually had Medicaid contracts or contracts with MCOs.**

CILs without Medicaid or MCO contracts usually transitioned fewer individuals compared to CILs with MCO contracts. For CILs primarily using Title VII Subchapter B and Subchapter C funds for transition work, including those who supplemented their funding through other means, institutional transitions were noted as often being financially challenging. Some CILs did as much transition work as possible, but they were not able to expand this area of work due to budget limitations. A few mentioned that the new core service was an unfunded mandate and although institutional transition has always been a CIL service, the specification of it as a separate service, without dedicated funding, meant stretching their budgets even further.

Of the 57 CILs in the survey, only 19 had contracts with MCOs for transition and/or diversion services. Five other CILs were actively pursuing individual relationships with MCOs and two CILs were working with consortiums to develop contracts with MCOs. The

CILs with MCO contracts were not always contracted to do the full range of transition and/or diversion work, but often only a part of the work. The services CILs were contracted for included: outreach, the relocation itself, follow-up, personal attendant services, peer-mentoring, independent living skills training, home modifications, assistive technology assessments, care coordination, and transportation.

When the MCO only paid for a portion of the transition – for example the relocation – CILs used other funds to pay for additional household items and provide ongoing support that segued into diversion work along the independent living continuum. This diversion work was not usually funded by the MCO. CILs with MCO contracts estimated that contracts paid for 20% to 100% of their institutional transitions. This variance related to the type of services contracted for and the number of referrals the CIL received from the MCO.

## How CILs Obtained Managed Care Contracts

### **19) Most CILs with an MCO contract told us that they had actively reached out to the state or the MCO to develop and secure the contract.**

The CILs with MCO contracts talked about cultivating contacts and relationships, meeting directly with funding decision makers including CEOs, and working with state CIL networks to advocate for the rights of CILs to provide transition services through the managed care structures. CILs shared different experiences based on their state and the Medicaid managed care program. Some CILs advocated for Centers to be MCO vendors but were prohibited by state regulations. Other CILs emphasized the value of adding other services to relocations authorized by MCOs.

In general, CILs with MCOs or health care company contracts described having strong business practices, highly trained staff, and service and performance data to facilitate the acquisition and retention of these contracts. Some CILs were particularly innovative in marketing to MCOs by highlighting unique resources (such as fitness centers) or programs (including peer-mentoring) or facilities (including housing or skill training centers). Some CILs previously had contracts with MCOs that ended for various reasons.

CILs with MCO contracts were not part of a consortium for the purpose of securing funding. Only two CILs discussed pending efforts to create a consortium for a funding contract opportunities with a health care insurer. In general, CILs with MCO and health insurer contracts had direct contracts between their organization and the contracting company.

### **20) Some CILs desired the opportunity to work with managed care and health care companies, but indicated it was not possible based on state level policies, the way MCOs structured their own work, or other factors.**

A few CILs were prevented from increasing their institutional transition work because their state lacked a strong or well-funded Medicaid program or well-structured managed care program. Others told us that state policies did not permit contracting with CILs or that MCOs decided to not use CILs as vendors. Still others indicated that MCOs in their states did not sub-contract with community-based organizations like CILs but hired staff in-house to do this work.

## What CILs are Contracted to Do

### **21) CILs that had contracts with MCOs were contracted to do a range of work.**

Some CILs reported contracts for the full transition, from preparing for and moving out of the institution through a specific post-transition follow-up period. Others reported being contracted to provide specific services such as personal attendant services or peer-to-peer support services. A few CILs had contracts to do diversion work with individuals needing support to remain in the community including independent living skills, home modifications, assistive technology, or peer to peer supports.

### **22) Most CILs indicated that contracts did not change the services provided or the assessment of outcomes.**

Most expressed that contracts extended their work, and some CILs noted they had to follow the funder's requirements in terms of paperwork and reporting. Some CILs were required to hand over certain aspects of the transition they previously handled to credentialed professionals like nurses.

Most CILs were using the same standards for assessing outcomes as they always had, but others indicated external payers requested additional data related to meeting transition goals and health and medical outcomes. However, one CIL highlighted the problematic nature of each MCO determining how to measure or evaluate a successful transition, noting that relocating after a two-week stay in a rehabilitation hospital was counted the same as moving out of a nursing home after several years of residency. Another CIL indicated working with their MCO partner to strengthen their outcome measures to extend beyond the medical outcomes to personal and social ones.

## Financial Results of Managed Care Contracts

### **23) Nearly all of the CILs had contracts indicated that they did more transition work, but did not financially profit from institutional transition work. For most, it was budget neutral. For others, contracts led to a reduction in revenue.**

Most CILs with Medicaid contracts or contracts with MCOs indicated that these funds permitted more institutional transitions each year and sometimes allowed the hiring of more staff than Title VII funds alone. Other CILs said their Medicaid contracts were in place for quite a long time, which kept the number of transitions steady but did not increase them. In general, CILs with contracts stated that these contracts were critical to funding their transition and diversion work. However at least one CIL with an MCO contract shared that the amount of transition work declined because the MCO did not understand how to do transitions.

However, many CILs with Medicaid and MCO contracts expressed that even though their annual revenue increased, the transition work remained budget neutral. Only a few CILs found ways to create excess income through these contracts to support other CIL programs and services. Some CILs stated their revenue related to transition work decreased because the MCO did the bulk of the relocation work and contracted with the CIL for a small set of transition-related services.

In addition to not seeing profit despite securing contracts with MCOs, some CILs never received referrals for transition work. This was attributed to the MCO's lack of organization and lack of concern with transitions and/or deciding to refer to another organization rather than the CIL.

**24) Some CILs told us that MCO funding did not cover the full transition cost or provide full reimbursement for CIL services.**

A few CILs spoke about billing practices with MCOs. Some CILs indicated a positive billing experience, while others did not. The latter said MCOs often declined to pay or reimburse CILs for goods or services they believed were not required for the transition such as home modifications. Still others indicated that the MCO only contracted for certain services such as transition coordination, but the CIL also provides other services, particularly when the MCO requires the consumer to find their own community resources – such as help finding housing or peer-support that is not paid for by the MCO (and possibly not billed for by the CIL).

**25) Both CILs with and without Medicaid or MCO contracts often sought additional funds for institutional transitions from other sources or used Title VII funds.**

Many CILs noted pursuing local foundations for grants, working with businesses to obtain donations and price discounts, holding fundraisers, and transferring income from fee-for-service programs to pay for institutional transitions and diversions. Some CILs with Medicaid contracts indicated the funding allotment provided by Medicaid was too low to pay for the full transition. Others indicated that the MCO or health insurer only paid for a certain set of transition costs and did not fund the type of wrap-around services believed to be necessary for a successful transition.

## **CILs Views on Working with Managed Care Companies**

**26) CILs with MCO contracts had mixed views on them as partnering organizations.**

Some CILs had positive experiences working with their MCO partner, while others did not. Reasons for these different experiences varied. Those CILs with the most positive experiences reported working with MCO personnel who were open to working with and learning from the CIL. Those with more negative experiences reported, for example, the MCOs were disorganized, did not really understand the transition process, or were working at an MCO company located outside of their community making it difficult to understand local issues and concerns. At least one CIL obtained contracts with MCOs and then decided not to work with the MCOs due to these types of difficulties. Another CIL noted MCOs in their state transition individuals from nursing homes to assisted living, not fully understanding the difference between that and an independent residence.

Additional frustrations among CILs were seen with MCOs ability to define transition. CILs said the MCOs definition of transition is often truncated and/or may include relocations from temporary stays such as leaving a rehabilitation hospital after a few weeks of care to return home or from a nursing home to an assisted living facility. CILs believed the MFP definition of transitions was stronger and should be retained by the state.



## Technical Assistance Needs

In general, CILs indicated that technical assistance would be beneficial in a range of areas including: best practices in working with MCOs and managed care companies; best practices in transition work – including post transition; learning from centers who are excelling in areas they find challenging; and additional training and resources related to areas such as how to move into the role of service provider without mission creep. Key findings are presented below.

### **27) CILs expressed needing technical assistance to secure funding and to work with health insurance companies and MCOs.**

Primary funding issues mentioned were not knowing how to access additional funding streams and the need for funds to market services. The lack of funding was viewed as a roadblock to working with health plans due to not being able to finance the upfront costs of transitions prior to health plan reimbursements.

In addition to funding concerns, CILs are unsure of how to approach and begin building relationships with health plans. In some instances, where CILs have relationships with health plans, they are not receiving funding from them to provide services. Therefore, there is a need for CILs to better understand how to market the CIL and services to health plans for funding. This highlights many CILs' concerns to improve marketing efforts. Centers were also concerned that working with health plans could lead to mission creeping and compromising their identity as a CIL.

### **28) Many CILs are interested in receiving additional training for transitions and diversions work.**

For transitions, CILs told us they were concerned with training staff on how to discuss transitions with individuals in institutions, understanding their legal rights and the rights of consumers in nursing homes, and how to improve capacity for transition work since staffing is often limited. For diversions, many CILs mentioned needing to better understand and identify individuals who are at-risk. Additionally, some CILs acknowledged that they struggle to define diversion and think there should be more of a consensus of services to be provided.

## Promising Practices

Discussions with CILs revealed practices being used to support the development and sustainment of relationships and contracts with MCOs and health plans. Below is a list of practices identified as having promise and potential usefulness to other CILs.

1. Engaging with the state and its planning process regarding how it will structure its Medicaid managed care program including contracting with community-based organizations – specifically CILs – as vendors for institutional transition and diversion work.

2. Actively building relationships with MCO leads as they identify vendors for institutional transition and diversion work. In states with multiple MCOs, this may include developing relationships with all of the MCOs or strategically targeting one or more.
3. Identifying and selling CIL institutional transition and diversion services – both core services (e.g. peer-mentoring, independent living skills training) as well as unique resources (e.g. fitness centers, skills training in home environments).
4. Developing additional services to market and sell to MCOs and health plans that draw from CIL expertise. Examples include a housing coordination service, a transition coordinator service, an assistive technology assessment service, durable medical equipment repair shop, or a wheelchair seating clinic. Services like these that have a clear set of defined activities, scope of services, and time frame that can be billed for and may yield additional referrals to CILs.
5. Implementing formal MOUs with community partner organizations to prepare for future funding opportunities in order to bid as a consortium. MOUs for a consortium across partners may be developed in preparation for a vendor contract or bi-lateral MOUs may be developed between a CIL and individual partners to strengthen relationships and adeptly respond to bids for vendors.
6. Upgrading CIL staff credentials and skill sets to be eligible to contract as vendors. This may include things like obtaining transition coordinator credentials, hiring more highly trained staff, or repositioning staff into different roles.
7. Updating or upgrading third-party billing processes and accounting processes to show viability as an MCO vendor and to appropriately track and bill MCOs and health plans for vendor services.
8. Identifying discrete services that are not being billed to MCOs and health plans related to transition and diversion work, but could possibly be billed. This may include peer-mentoring, follow-up with consumers, provision of assistive technology or other activities that may be offered as part of the CILs mission but not currently funded by the MCO or health plan.
9. Creating a gold standard for case notes to ensure acceptance from funders and meet the standards of their auditing groups. This may require considerable staff training, use of tools and checklists, and regular weekly supervised reviews to support these higher standards.
10. Updating or upgrading outcome data collection to show both cost/benefit and health-related outcomes that occur after institutional transition and diversion work as well as traditional independent living outcomes such as community participation and engagement including employment, volunteering, or other roles.
11. Using evaluation data to show added value of CIL services. For example, in a consumer choice model, evaluating differences in outcomes and sustained community-living for consumers who choose to work with the CIL for an initial 90-day period post institutional



transition compared to those who continue to receive support and assistance from the CIL beyond the 90 days.

12. Monitoring MCO contracts to determine the amount of transitions completed and additional revenue generated to understand the proportion of transition covered by external funding contracts. This entails both tracking the total cost of an institutional transition and distinguishing funds provided by MCOs and health plans from those contributed through other means that might not be reimbursed by the MCO or health plan.
13. Determining the importance of, and right amount of, profit margin obtained through a contract with an MCO or health plan to make the contract successful. This may include determining that the CIL will take no overhead or administrative fee for the transition or diversion work and pay for staff time through other funds. In this model, the CIL may devise a means for the flat rate or billable amount paid by the MCO or health plan to support consumer costs for the transition only. Or, the CIL may determine that a modest administrative fee will be charge for each MCO or health plan consumer and that fee will be routed into a fund to pay for supplemental services or goods the CIL provides to consumers. Profit margin goals may be considered within the context of other revenue streams.
14. Renewing or revising contracts with MCOs and health plans that are not yielding referrals for institutional transition by modifying the services the CIL contracts for or the approach the CIL takes to working with the MCO/health plan. This may include the CIL not insisting on being in control of the MCO/health plan member's case but rather treating the member as a regular CIL consumer and assisting that person as the CIL normally would, advocating for what they need and want to do. In this approach, the CIL bills for services provided as a vendor based on the contractual agreement of what is a reimbursable service or a set per-member fee. Depending on the vendor agreement, all CIL services may not be reimbursable.
15. Selling diversion services in general – for persons at risk of re-hospitalization, nursing home placement – and in particular for persons with disabilities in higher-risk situations such as those living in homeless shelters, domestic violence shelters, natural disaster emergency shelters, or leaving incarceration.
16. Educating MCOs and health plans about the independent living approach through joint training between CIL staff and MCO/health plan staff, participation in interdisciplinary team meetings for transitioning consumers, and other shared engagement opportunities. In some cases, this may involve advocacy but in general this approach is focused on the benefits to the consumer and the MCO or health plan by emphasizing the flow of individuals in and out of institutional care to reduce costs while at the same time improving quality of life and independence for individuals.
17. Co-locating CIL staff at major institutions such as hospitals to assist with discharge planning and help divert individuals from initial institutionalization post-hospital stay

and/or begin preparing for community transition at the beginning of an institutional placement.

18. Working with other local and regional CILs in a partnership perspective and the MCO/health plan to identify universal technical specification for contracting on specific services such as assistive technology assessment and home modifications. This model develops a best practice protocol for technical specifications for each CIL's contract by agreeing on how to term and describe individual service components and identifying which of these fees are billable. It ensures that contracts for like services are operationalized the same way for each contracted CIL.
19. Thinking outside of the box about how to leverage CIL expertise. For example, this may include working with non-traditional partners, identifying low-cost, low-tech solutions, and entering new marketplaces.

## Appendix A. Institutional Transition Stories

CILs shared examples of successful institutional transitions. Below is a selection of these stories lightly edited for clarity and to protect the identity of consumers. We provide these as context for understanding the key findings in this report.

### Story A:

One of our consumers had family members that were not supportive of her or her living in the community. Her family placed her into a local nursing home that has a reputation for providing inadequate care. This person developed pressure sores and the family did not visit or provide certain advocacy services that she needed. Basically, she was giving up. We had our counselors go in and talk with her – she expressed a need and a desire to go back into the community. We then were able to get her into a community with other persons with disabilities.

She was provided a two-bedroom apartment along with 12 hours of home health care assistance. She lived near a bus stop. Once she was up to it, would go and catch the bus to do whatever business she needed to do. She also had the ability, with a donated computer, to pay bills and that kind of thing online. But, she just had the need to get out sometimes, catch the bus to the mall, to the movies, and so forth. So we transitioned her out of the nursing home back into the community and helped her to develop friendships. She's doing well today.

### Story B:

A year ago we had a gentleman that had fallen from a roof and ended up with a spinal cord injury. He was in the hospital for some time and then in rehabilitation. We started following him through the rehabilitation, met him, and talked to him. He could not go back to the home he owned without the home being remodeled to become accessible. He was asking “What do I do? Where do I go?” One of the solutions was to go into a nursing home until we found an apartment. We could help him move into a nursing home and then try to raise money or look for the funds that would help to remodel his home (put a ramp outside and fix everything inside so he could move around with a wheelchair). It took probably six or seven months but through the Spinal Cord Association the CIL got a grant for door adjustments and a ramp. He had great support from his family who took care of everything inside the house. The individual is home and happy.

### Story C:

There was a woman who had surgery at a hospital about 90 minutes from her home and the surgery went wrong. She needed to go through rehabilitation – she was in very bad shape – and was going to be sent to a facility near the hospital. Her family came to the CIL to help her transition back to her home community for rehabilitation and eventually back into her home. Initially, our local long-term care facilities that provided rehabilitation refused to care for her because they said that they didn't have the medical capacity. It took the CIL knowing people, calling everybody that needed to be called, and saying “you need to make this happen so that this woman can have care in her own town.” The community partners were the relationships that helped advocate for the individual. The long-term care facilities were not CIL partners in the

transition in the beginning – but one eventually became a partner. The long-term care facility worked very hard to get this woman healthy and back into her own home again, where she is now. This took a large amount of advocacy. It's not like "Oh, I know this person who can do this service for you and this service will happen in your home and we can set that up." That's easy enough but the transition itself, because of the distance, was an issue. It's just putting your head down and figuring out who you know and how you're going to make this happen.

### Story D:

A senior woman was recently injured in a car accident. She was transferred to a nursing facility when she came out of rehabilitation, so she lost her apartment and most of her belongings. After the initial meeting we were able to gather the information needed to begin discharge planning such as income level, housing preference, budgeting, and transportation and household needs. We then set up meetings with her MCO, family, ombudsman and nursing home social worker. After a third discharge planning meeting, we were able to get her safely and happily back into the community. The first step was to register her for institutional Medicaid. Then next, meet with her care coordinator at the MCO, and we discussed and decided on what she would need in order to make this a successful and lasting transition. The IL Specialist found an apartment for the consumer and assisted with completing the application process. The IL Specialist was then able to purchase, with MCO & Center funds, what was needed for the apartment: bed, bedding, kitchenware etc. Then, assisted consumer in interviewing and hiring an attendant. Finally, the consumer was able to transition to her apartment in her community.

### Story E:

A senior veteran had a stroke and the court appointed co-guardians/co-conservators, who convinced the court that he had Stage 4 Alzheimer's disease. His family contacted the Center for assistance to advocate on his behalf to return home and live with his wife of 20 years. However, it was believed the nursing facility was the least restrictive setting. We assisted the wife with preparing and filing a petition for the court to set aside the judgment and order an independent psychological evaluation. The court refused to set aside the judgment, and we referred his wife to a private attorney, who provided legal services at a substantially reduced rate. We provided the attorney with technical assistance on the state's guardianship laws and strongly advocated for an independent psychological evaluation. After the independent psychological evaluation contradicted the claim of Alzheimer's disease or related dementia, we assisted with his transition to his step-daughter's home. This transition required assistive technology through our Center; transportation to medical appointments using funds from a Veterans program; advocacy for the return of his personal belongings; referrals to the state Protection and Advocacy, the state Attorney General, the Veterans Commission; referral services for Home Health; and research for legal assistance to mitigate the pending foreclosure of his home.

## Appendix B. Institutional Diversion Stories

CILs were asked to give us examples of successful institutional diversions. Below is a selection of these stories edited for clarity and to protect the identity of consumers. We provide these as context for understanding the key findings in this report.

### Story A:

A senior woman was referred to the CIL from a partner program. She needed help with her housing situation and risked eviction because of her low income and the cost of rent. Her IL counselor learned that she was paralyzed due to a stroke, had spent time in a skilled nursing facility, and returned home only to find out that her husband abandoned her without warning. She was left with nothing except the apartment they rented together. Her SSI was \$680 a month, and the monthly rent for the apartment was \$1,300 plus utilities. With help from the family, we were able to collect all the necessary documents to apply for the Olmstead Housing Subsidy. The consumer was eligible and was successfully enrolled into the program, saving her from eviction and re-institutionalization.

### Story B:

An individual contacted us post-hurricane because they were behind on rent and looking for another housing opportunity. The consumer was willing to go on a two-year waitlist, couch surf or be homeless. And, it was simply because the lights went off in their home. They felt unsafe and were willing to become homeless. As a CIL, we understand all disability types and got to the core of the issue. The CIL went through an action plan workbook with the consumer and connected them to financial services. They kept their housing and was diverted from possibly entering a nursing home or assisted facility, or just being homeless. A lot of times CILs are responsible for those small things that require effort that have a tremendous impact. It's not like a machine that someone can say "alright this person has an issue and at the end this is the result." It's an individualized process for each person.

### Story C:

A middle aged woman had a bunch of drastic medical complications including a stroke that resulted in a traumatic brain injury. She was in the hospital for a long time and then was in the rehabilitation unit of the hospital for a long time. She did not want to go to a skilled nursing facility, she wanted to go home. And luckily we were made aware of her situation, and we met with her and her children to develop a plan with an array of services including some home modifications recommendations. We worked with her and the hospital's social workers to get her ready to go home. This included exploring vehicle modifications and acquiring her driver's license again so she would have access to her own vehicle in the future. It took time and there were some frustrations, but she returned home. And, she is living in the community to this day.

### Story D:

There was an older couple, and their son reached out to our CIL because he was concerned about his parents. The father was having some health problems, and there was concern that the mother

might have early stages of Alzheimer's. But, they did not want to go into an institution – they did not want to leave their home. Our advocate met with them in their home almost daily, and talked to them about what they would need to remain in their home. The advocate connected them with cleaning companies, a local firm to help with ramps and needed items in the home, and got resources in place to modify the home to make it more livable. They seemed very happy with the services and actually did stay in their home. They reach out and talk to the advocate about other services, so our CIL has kept in touch with them. It was a successful experience not just in terms of keeping the couple out of the nursing home, but also in terms of making them aware of community resources. He was a Veteran, so it was connecting him with some of the local V.A. resources to support him as well.

### Story E:

One success story involves an older male with multiple disabilities including a traumatic brain injury, low cognitive function, obesity, limited mobility using a walker, and several others. This participant worked with us for many years receiving peer support, advocacy, independent living skills training, and adaptive devices. The participant lived in a small rural community with an inaccessible bathroom. In the short term, this participant was using adaptive devices to access and use the bathroom. However, due to his declining medical conditions and mobility, he had a fall in the bathroom. The fall did not require hospitalization or nursing home care, but prompted our agency to provide additional services. During this time our Independent Living Specialist met with the apartment manager, maintenance person, community health nurse, and Long Term Services and Support (LTSS) Specialist to form a team and discuss options for making the participant's bathroom fully accessible with a walk-in shower, ADA accessible toilet, grab bars, and a higher sink. The apartment complex was able to fund this modification and utilized the CIL's and the LTSS's knowledge of accessible bathrooms for guidance. After the modifications were complete, the participant was able to safely use his bathroom. A plan was put in place for extra supports and services while he continued to recover, improve, and live independently in his hometown community.

## Appendix C. Unsuccessful Institutional Transition Stories

CILs were asked for examples of unsuccessful institutional transitions to better understand the challenges related to this work. Below is a selection of these stories edited for clarity and to protect the identity of consumers. We provide these as context for understanding the key findings in this report.

### Story A:

The CIL worked with a younger gentleman who had sustained a spinal cord injury. He went from incredibly independent and working full-time to having this significant injury that turned his world upside down. Throughout his time in the nursing home, he worked extensively on physical therapy and occupational therapy. He was motivated to get back into his own independent living situation. We got him set up with a fully accessible apartment through the local housing authorities and got home health services in place. We worked to setup home delivered meals and quite a bit of support through the long term waiver program. After a couple of months living independently, he realized he was he was struggling. The amount of support a home health agency provided did not really give him the full flexibility he wanted. There was also fear and anxiety in terms of being home alone and not really having supports around the clock. And, he recognized he was personally more comfortable in the nursing home setting.

### Story B:

One really horrible example was a consumer who went through an unsafe discharge from the nursing home. The Center tried to prevent this from happening; however, sometimes it is beyond our control. The nursing home discharged the consumer on a Friday and by Monday, we had to call 911. The consumer was admitted back to the hospital and was readmitted back to the institution just to find that it was an unsafe discharge where Adult Protective Services was then involved to make sure that this person did not have to face another unsafe discharge. So this is a prime example of the social worker and the nursing home staff not communicating and working with either the transition specialist or the care manager. This can happen – they get hospitalized and sent back to the nursing facility.

### Story C:

An individual moved down here from another state. He did not have any housing, and so he was in the middle of the winter living in his car. Our CIL worked with him to get him on a list for housing. However, he ended up giving up and moving back to the state he was from because he was getting close to the top of a housing list there. So we thought although it was not successful in our state, he will at least find housing somewhere else. And then, about six months later, he came back to our CIL and had a medical emergency in the office. We ended up calling an ambulance for him. And, he's now in a situation where he was released to a nursing home and will not be released from the nursing home until he has housing. Unfortunately, he's not near the top of any list. I would not say it's unsuccessful yet because we are still working with the consumer to find housing.