Texas Council
of Community Centers

Local Intellectual and Developmental Disability Authorities:

Targeted Case Management Role

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In Community Every Day

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STATUTORY ROLE IN A CHANGING SYSTEM

The service delivery system for Texans with intellectual and developmental disabilities (IDD) is slated to undergo significant changes in the coming years; most notably, Home and Community-based Services (HCS) and Texas Home Living (TxHmL) services and supports will be shifted from services managed by the Department of Aging and Disability Services (DADS) to services managed by insurance companies (referred to as "managed care"). In this changing environment, the assessment, service planning, and monitoring role of the Local Intellectual and Developmental Disability Authority (LIDDA), as the local agent of the state, becomes even more important to ensuring continuity of services over time for this vulnerable population.

What is Intellectual Disability?

Formerly described by the outdated term "mental retardation" (now considered disrespectful), intellectual disability is a condition characterized by significant limitations in both intellectual functioning (reasoning, learning, problem solving) and adaptive behavior (practical and social skills).

Most often evident at birth or in the very early years of a child's life, the condition must have occurred before age 18. Causes may include trauma (before or after birth); infections; intra-uterine exposure to alcohol, cocaine or other drugs; and genetic conditions, such as Down syndrome.

From domestic violence to safe, independent living

Debra*, a 52-year old woman with an intellectual disability and mental health conditions, experienced a crisis due to domestic violence committed against her. A LIDDA case manager secured placement for Debra at the LIDDA's crisis respite program, and then, at Debra's request, in an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF-IID).

After a period of residence in the ICF-IID, Debra transitioned back to community living and is currently enrolled in the Community First Choice (CFC) program to continue developing independent living skills. The case manager monitors Debra's psychiatric appointments and medication regimen adherence through a person-directed plan.

IDD service delivery system changes in the future must ensure the statutorily authorized LIDDA independent Targeted Case Management (TCM) functions successfully interact with various elements of managed care service delivery.

Over time, this independent third-party function has proven essential to ensuring there is a local agent of the state to provide assessment, service planning, and monitoring of services for persons with IDD. This function is particularly important as insurance companies play a greater role in authorizing and paying for services people with IDD count on every day.

Of note, a first step of the Texas IDD system redesign

was implementation of Community First Choice (CFC), a program designed to provide cost-effective personal assistance and habilitation services in home and community-based settings. CFC was implemented on June 1, 2015. In authorizing implementation of CFC through Senate Bill 7, the 83rd Legislature directed independent service coordination (case management) through LIDDAs, building on the role LIDDAs fulfill in the HCS and TxHmL Waiver Programs.

LIDDA TCM DIFFERS FROM MCO SERVICE COORDINATION

Because insurance companies, acting as Managed Care Organizations (MCOs), rely on service coordinators with clinical qualifications, such as Registered Nurses, and higher caseloads across wide geographic areas, it would not be cost effective or feasible for MCOs to provide the same kind of personal, intensive, in person TCM that LIDDAs currently provide in every local service area across Texas.

Many Texans with IDD receive STAR+PLUS service coordination through MCOs, in addition to receiving TCM from their LIDDA. Service coordination as delivered by an MCO is very different from TCM as delivered by a LIDDA. A few of the distinguishing factors between MCO service coordination and LIDDA TCM include focus of services, the nature of the individual's relationship to his or her service coordinator/case manager, and qualifications and experience of case managers.

From loss of caregiver and destabilization to secure community living

Amber, a 30-year old woman with an intellectual disability, was thrown into a crisis upon the death of her grandmother, who acted as Amber's primary caregiver. Amber was at risk of institutionalization until a LIDDA case manager intervened and secured an HCS diversion slot for her. Amber moved into a small HCS group home in her local community.

In this new setting, which resembles a family home, Amber has her own bedroom, attends day habilitation on a regular basis, and receives the support and supervision she needs. Amber is very satisfied with her arrangements.

Focus of Services. Service coordination is provided by an MCO to its members only, with a primary focus on medical services. Service coordinators work with individuals to ensure health care needs are met. Service coordinators assess individuals' needs, participate in service plan development and authorizations, and coordinate with medical providers.

TCM by LIDDAs is provided for individuals regardless of insurance or payer source. While an MCO Service Coordinator leans into the coordination of medical services, the LIDDA case manager leans into needed social, educational, and other supports.

In addition to conducting in person visits with the individual, a case manager makes other collateral contacts with the legally authorized representative (a parent or guardian), family, comprehensive providers (including residential services), non-Medicaid resources and others in the community.

These contacts take place in homes, job sites, hospitals, jails, nursing facilities, clinics, schools, day programs and state facilities.

Nature of the relationship. The relationship between an individual and his or her MCO service coordinator can be transitory and limited. Many circumstances can lead to the severing or changing of this relationship, including the individual switching MCOs, the individual losing Medicaid coverage (temporarily or permanently), the MCO changing ownership, or the MCO withdrawing from the market. Additionally, due to large caseload sizes and geographically vast service delivery areas, an MCO service coordinator will often make contact via telephone, rather than through an in person visit.

From undiagnosed health situation to positive outcomes

A LIDDA case manager visited Larry, a 45-year old with an intellectual disability, monthly in various settings. During a visit at Larry's day habilitation site, the case manager noticed Larry's typical alert, cheerful demeanor had changed. The case manager then contacted Larry's group home and learned that Larry had recently fallen in the home. The case manager arranged for Larry's Service Planning Team to implement environmental protections pending the completion of a medical workup. A wheelchair was ordered for use in the day habilitation program and rugs were secured in the group home. A Neurologist diagnosed fluid on Larry's brain and surgery was performed to install a shunt.

Following surgery, the case manager recognized the immediate return of Larry's happy, engaging personality.

FY 2015 LIDDA TCM Contacts

Unduplicated Count of Individuals	45,381
Average Contact (Individual +Collateral) Per Year	30.33
Average Contacts with Individual Per Year	13.78
Average Face-to-Face Contacts with Individual Per Year	11.27
Average Collateral Only Contacts Per Year	16.55

The relationship between an individual and his or her LIDDA case manager tends to be stable and personal. A LIDDA is a community resource and an arm of the state. An individual does not switch LIDDAs (unless the individual moves to a different area of the state), just as an individual does not switch local Police Departments or hospitals. If an individual loses Medicaid eligibility, the LIDDA works with the person to reinstate Medicaid if appropriate and continues to monitor the person's health and well-being.

Additionally, the typical caseload for each LIDDA case manager is 40 individuals, much lower than the typical ratio of MCO service coordinators to members. The low ratio allows LIDDA case managers to provide comprehensive support and develop a personal relationship with each individual. While in person visits are required at least once every 90 days, the needs of individuals often prompt more frequent contact. In FY 2015, LIDDA case managers conducted in person visits with each individual nearly every month.

Qualifications and Experience. Because MCO service coordination focuses on health care needs, with particular emphasis on medical assessments of individual needs and authorization of services, MCOs employ registered nurses and other licensed professionals as service coordinators.

Successful transition from institution to community life

When Kim identified her desire to move out of a State Supported Living Center and into community, a LIDDA case manager worked closely with Kim, her family, and service providers to ensure a successful transition. The case manager met with Kim monthly, conducted onsite visits of all community service delivery sites to ensure proper supports for Kim were in place, and reviewed the community waiver provider's implementation plan.

After Kim moved into an HCS group home, the case manager continued to visit her monthly and reports Kim has achieved new levels of independence. She is trying different foods, wearing new clothing styles, and has connected to a faith community.

The broader focus of LIDDA case managers is reflected in qualifications for case managers. Generally, a case manager must have a bachelor's or advanced degree from an accredited institution with a major in social, behavioral, or a human service field. As the state's "boots on the ground," LIDDA case managers become experts on resources available in their local communities. They also interact regularly with local private providers of comprehensive IDD services on behalf of clients, creating levels of partnership and trust necessary to address high-needs situations, such as client crises or provider closures, as they arise.

Additionally, LIDDA case managers provide intensive case management to individuals with particularly high needs. Residents of institutions (Nursing Facilities or State Supported Living Centers) who are transitioning to a community Medicaid waiver program or community-based ICF-IID receive Enhanced Community Coordination from LIDDA case managers. Enhanced Community Coordination involves intensive support from a case manager to ensure successful transition to the community and prevent re-admission to the institution. Supports include frequent (at least monthly) monitoring of all services and supports before and after transition and close collaboration with the individual's Service Planning Team.

Case managers responsible for Enhanced Community Coordination must have extensive experience in providing case management to individuals with IDD, including those who have complex medical needs, and must maintain caseloads at or below 30 individuals.

LIDDA MONITORING ROLE

A strong monitoring role is critical for the safety and well-being of Texans with IDD. People with intellectual disabilities face higher rates of abuse, neglect, and exploitation than the general population and people of other disability types.

Studies indicate people with developmental disabilities are 4 to 10 times more likely to be abused than peers without disabilities and tend to be abused more frequently, are abused for longer periods of

time, are less likely to access the justice system, and are more likely to be abused by a caregiver or someone they know. A 2012 systemic review of relevant studies published in The Lancet concluded that "individuals with intellectual [disabilities] had the highest population rates of violence compared with both the general population *and individuals with other disability types*" (emphasis added).[1]

From cycle of disciplinary actions in school to successful student

Javi, a 7-year old boy with an intellectual disability, was struggling in school. A LIDDA case manager went to Javi's school to observe his learning environment first hand. The case manager learned that the school had exhausted all known resources to help Javi control his aggressive behaviors. These behavioral issues were causing Javi to be sent home from school almost daily; he was at risk of being institutionalized. The case manager located and scheduled an appointment with a psychiatrist who prescribed an effective treatment regimen.

Javi is now able to function and learn in his public educational environment. The case manager continues to advocate for additional resources to enhance Javi's functionality in all aspects of his life and increase his life satisfaction.

For these reasons, it is necessary for the service delivery system for people with IDD in Texas to include in person monitoring of services by case managers experienced with IDD issues. TCM must occur in the settings where people live, work, and receive services, and include regular interactions with caregivers.

Through the monitoring role, LIDDA case managers ensure that individuals with IDD receive needed services, evaluate the effectiveness and adequacy of services, and determine if identified outcomes are meeting the individual's needs and desires. Ensuring the individual receives needed services requires the LIDDA case manager to monitor on a frequent basis across all locations where the individual receives services.

RECOMMENDATIONS TO IMPROVE LIDDA MONITORING FUNCTION

Texans with IDD would benefit from strengthened communications between DADS regulatory services, Department of Family and Protective Services (DFPS), Medicaid MCOs and LIDDAs to improve the local monitoring function.

Through its regulations of facilities, such as public and private ICF-IIDs, and of community-based programs for people with IDD, such as the HCS and TxHmL Waiver Programs, DADS plays a major role in ensuring health and safety of Texans with IDD. Similarly, DFPS Adult Protective Services is responsible for in-home and facility-based investigations of abuse, neglect, or exploitation of Texans with intellectual disabilities. Through the development of provider networks and authorization of

[1] Hughes K, Bellis MA, Jones L, Wood S, Bates G, Eckley L, McCoy E, Mikton C, Shakespeare T, Officer A. Prevalence and risk of violence against adults with disabilities: a systematic review and meta-analysis of observational studies. Lancet 2012; doi:10.1016/S0410-6736(11)61851-5.

services, MCOs play a significant role in service delivery for Texans with IDD and Medicaid coverage. When LIDDAs are working with an individual facing barriers to Medicaid acute care services, such as providers not accepting new patients or specialists not accepting patients with IDD, the LIDDA case manager and MCO service coordinator can work together to find solutions to best meet the needs of the individual.

Strengthened communication, collaboration and more clearly defined protocols among DADS, DFPS, MCOs and LIDDAs, would more effectively promote health and safety of Texans with IDD.

CONCLUSION

Local IDD Authorities are uniquely situated to perform the fundamental functions of targeted case management for people with IDD in our changing system. Because LIDDA case managers are local and conflict-free, they are able to provide consistent, in person monitoring over time and across locations to ensure the individual needs of each person are central to decisions about needed services, promoting effective outcomes and the opportunity to remain in community over the course of life.