



I/DD and Behavioral Health Service Gaps for Clients Experiencing Co-Occurring Disorders

for

Sedgwick County Developmental Disability Organization



Developmental
Disability Organization

*Sedgwick County...
working for you*

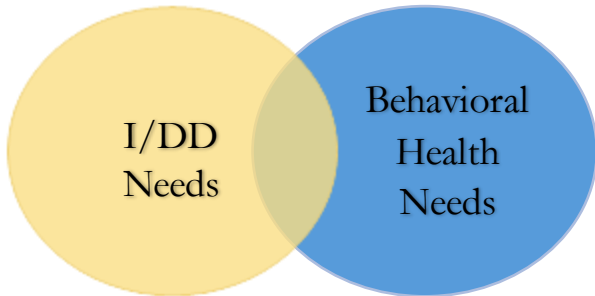
August 2016

Gaps for Clients with Co-Occurring Disorders

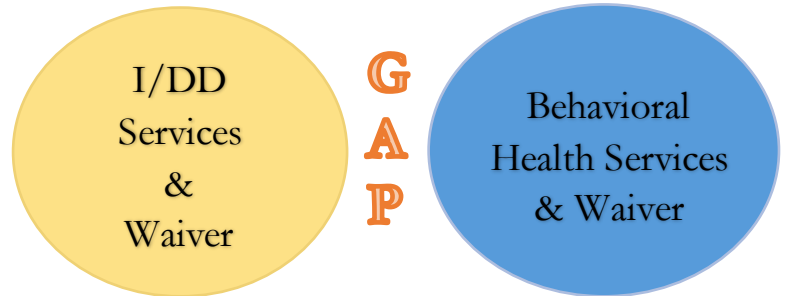
Background

Some of the most vulnerable citizens in our community are those who experience intellectual or developmental disabilities (I/DD). This population relies heavily on their families and other caregivers, and those family members and caregivers, in turn, rely heavily on the Sedgwick County Developmental Disability Organization (SCDDO) to help ensure quality of life and some degree of productivity in the community. A special subpopulation of those with I/DD issues are those who also suffer from behavioral/mental health issues simultaneously. These co-occurring issues magnify the difficulties experienced by this special group. While composing only a small part of the population, people with co-occurring disorders disproportionately affect the communities in which they reside because of the circles of influence radiating through both established systems and informal networks of family, friends, and caregivers. The health of a community is only as great as the health of its most vulnerable residents. Therefore, it is in the best interest of the community to help those with co-occurring disorders lead the healthiest life they can.

Clients Experiencing Co-Occurring Disorders



Services Available to Clients



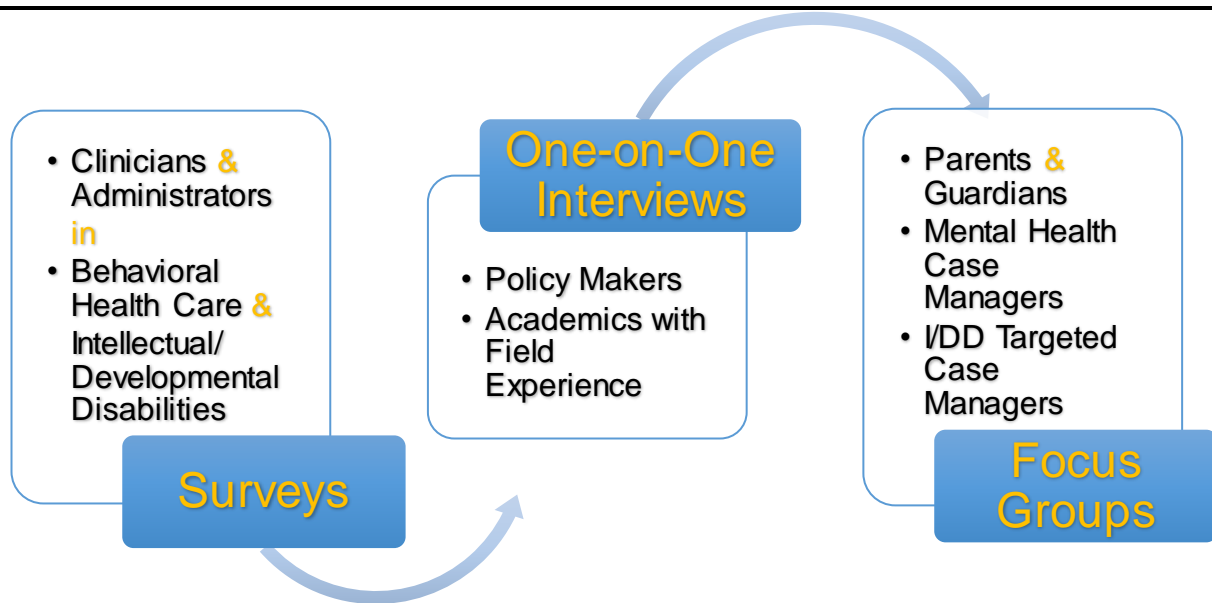
Unfortunately, this may be the one population that struggles more than any other to find a sustainable path to health and wellness. The combined and often compounded issues experienced by those with co-occurring disorders make sustained progress difficult.

It's like "trying to find your way in the dark during a crisis."

Adding to this already complex reality, is the fact that the systems that are supposed to help often do not provide coordinated care, making it difficult to do anything but survive or regress. It is in this context, that the SCDDO requested assistance from the Center for Applied Research and Evaluation (CARE) as part of Wichita State University's Community Engagement Institute (CEI). The SCDDO wanted to understand how those with co-occurring disorders experienced services in Sedgwick County. In this capacity, CARE conducted

an assessment of services and gaps in Sedgwick County for persons with co-occurring behavioral health and developmental disability issues. This evaluation included:

1. developing, administering and analyzing stakeholder surveys for two distinct populations (e.g., service providers, service recipients, etc.);
2. designing, conducting, and analyzing one-on-one interviews with service professionals and academics in the field; and
3. designing, conducting and analyzing three focus groups with stakeholders.



These evaluation activities were designed to provide information to the Sedgwick County CDDO and their partners on services and gaps for co-occurring behavioral health issues and developmental disabilities and possibilities for building the capacity to better address the needs of this population.

- Parents & Guardians
- Mental Health Case Managers
- I/DD Targeted Case Managers

The report that follows includes the results of all three evaluation activities. The executive summary coalesces the findings for all of the work, and Appendix B includes the raw results of the survey for those interested in specific responses. In order to ensure that all participants in each stage of the evaluation process operated under a common understanding of the topic, the following definition of behavioral health was used by the researchers:

For the purposes of this project, **behavioral health refers to factors that affect mental and emotional well-being most specifically; but also physical health in most cases. We are most interested in services related to substance use/abuse and mental illness.** While many persons with developmental disabilities may use substances and/or experience mental/emotional discomfort at times, the items in this survey are most relevant for persons who experience significant disruption in their lives and their ability to benefit fully from services for developmental disabilities because of substance abuse and/or mental illness.

Using this common definition allowed the participants to respond to prompts and questions with similar contexts in mind. That said, the respondents were chosen for each activity based on their diverse experiences with clients who experience co-occurring disorders. To ensure this diversity, the survey recruited both behavioral health clinicians/administrators and intellectual/developmental disability (I/DD) clinicians/administrators; the focus groups recruited family caretakers for clients with co-occurring disorders, behavioral health professionals, and I/DD professionals; and the interviews included both professionals and academics in the fields of behavioral health and I/DD work and training. In completing this work, 206 stakeholders were given the opportunity to report their experiences and contribute to the results reported here. For more information about specific methodologies for each activity, please see Appendix A.



Executive Summary

Throughout the course of this research, one theme was very clear across all the participants and across all three evaluation activities: the systems that help with each side of the co-occurring disorder (intellectual/developmental disability and behavioral health) do not adequately coordinate for the clients who need it. This lack of coordination is due to a number of structural and policy issues that make it more likely for information, procedures, and even people to fall through gaps that result in frustration, regressed progress, and sometimes tragedy.

Participants across all methods mentioned the need for better training and collaboration and the removal of the barriers that currently prevent or discourage cross-discipline cooperation in order to improve the system.

People with co-occurring disorders represent a relatively small percentage of both populations, which limits the exposure and experience of providers to the specific difficulties associated with treating these individuals. Combined with a lack of structural and policy-driven cohesion, this group ultimately ends up suffering more and impacting their communities more than might be expected given the size of the population. Training (and cross-discipline training) that addresses the unique needs of clients with co-occurring disorders as well as consistent documentation of plans and procedures that are usable in multiple contexts are two of the recommendations that stood out as important to consider.

Barriers to Access

- Wait lists
- Lack of understanding of co-occurring disorders
- Lack of training/cross training
- Lack of clear policies on who serves these clients
- Only allowed on one waiver
- Difficult to navigate system
- Denial of claims
- Lack of communication between providers
- Inadequate funding
- Current licensing of addiction as a separate field
- Lack of inpatient options
- Issues with providers (beliefs, attitudes)

Recommendations

- Increased communication/ collaboration between I/DD and Behavioral Health
- One stop point of entry
- Cross-training in both systems
- Removal of age limitations
- Decrease wait list
- Health Homes
- Streamline processes between providers
- Behavioral Health as a specialty within other disciplines
- Exposure during education
- Increased funding
- A summative cover sheet for plans of care for quick reference

Of particular interest is the perspective of the caretakers (parents and guardians) of people with co-occurring disorders because they are often intensely involved when a crisis happens. This may mean calling protective services (i.e. law enforcement or other resource) or attempting to de-escalate a crisis themselves or helping to problem-solve and recover some normalcy after a crisis. In any scenario, caretakers voluntarily work night and day to assist their loved ones through incredibly challenging circumstances, and they often feel alone and left to fend for themselves.

Parents & Guardians Note:

❖ *They have difficulty finding & keeping a good provider/case manager, which can be difficult for those with co-occurring disorders because they must re-adjust to new expectations, approaches, and personalities. Caretakers feel this stress as acutely (though differently) as the clients.*

❖ *Plans of care are not being utilized across systems, including health care & law enforcement, which leaves caretakers holding the bag when crises escalate because previously agreed upon procedures are not adhered to.*

❖ *The wait list forces caretakers to try and fill the gap between services, which often results in a loss of client progress and can lead to a feedback loop of distress and lowering functionality.*

Reductions in productivity, economic prosperity, and capacity to engage affects communities that do not support these caretakers.

The findings across all three methods (survey, interviews, and focus groups) paint a picture of a system serving clients with significant and complex issues and dedicated staff and caregivers who are straining against limited resources and policies that may not be aligned with client needs. Across all methods and respondents, the lack of communication/coordination among the I/DD and behavioral health systems, lack of training to adequately prepare staff in both to deal with complex needs, and concern about policies that cause silo-ing and gaps in services emerged as the primary themes. Participants across all three focus groups, in particular, expressed some degree of discouragement that clients often cannot get the services they need when they need them. Parents/guardians conveyed a definite sense of urgency, and also fatigue, related to needing to constantly fight to get minimum services for their children and, at times, for themselves.

Top Findings:

- **Co-occurring disorders represent significant and complex issues.**
- **Staff and caregivers struggle to find hope in an under-resourced system.**
- **Lack of communication and coordination lead to frustration, regression, and suffering.**
- **More training needs to be available for those who serve clients with co-occurring disorders.**
- **Parents and guardians often feel abandoned and discouraged.**
- **Providers feel discouraged that services are not available to clients when needed.**

On the positive side, participants across the methods identified continued discussions or regular meetings between the I/DD and behavioral health systems as a possible way to address the fragmentation that contributes to their concerns. One interviewee specifically named Sedgwick County as a community that is leading the way in bringing the systems together to collaborate for the benefit of clients.



This research provides a comprehensive, 360-degree view of the issue of gaps in services for individuals experiencing co-occurring disorders because it both quantifies areas of concern as well as reports the in-depth experiences of both providers and caretakers. Due to the relatively low incidence of co-occurring disorders, response rate to the survey was also relatively low. However, those who did respond are a fair approximation of providers and administrators in the field, who have experience with this population. In this respect, the respondents to the survey were in the best position to offer useful data about this issue. Considerations of future research should include an investigation of effective cross-training or cross-functional interventions, ways to support or equip caretakers more thoroughly, and ways to promote cohesion of response by providers for the contexts in which those with co-occurring disorders often find themselves.

“My biggest fear is that my child will outlive me and won’t be able to navigate the system to access the basic services he needs.”

to access the basic services he needs.”