

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



Developmental  
Disability Organization  
*Sedgwick County...  
working for you*

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## INTRODUCTION

### Context:

- Some of the most vulnerable citizens in our community are those who experience intellectual or developmental disabilities (I/DD).
- 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.
- In this context, the Sedgwick County Developmental Disability Organization (SCDDO) partnered with the Center for Applied Research and Evaluation (CARE) within Wichita State University's Community Engagement Institute (CEI) to understand how those with co-occurring disorders experienced services in Sedgwick County.

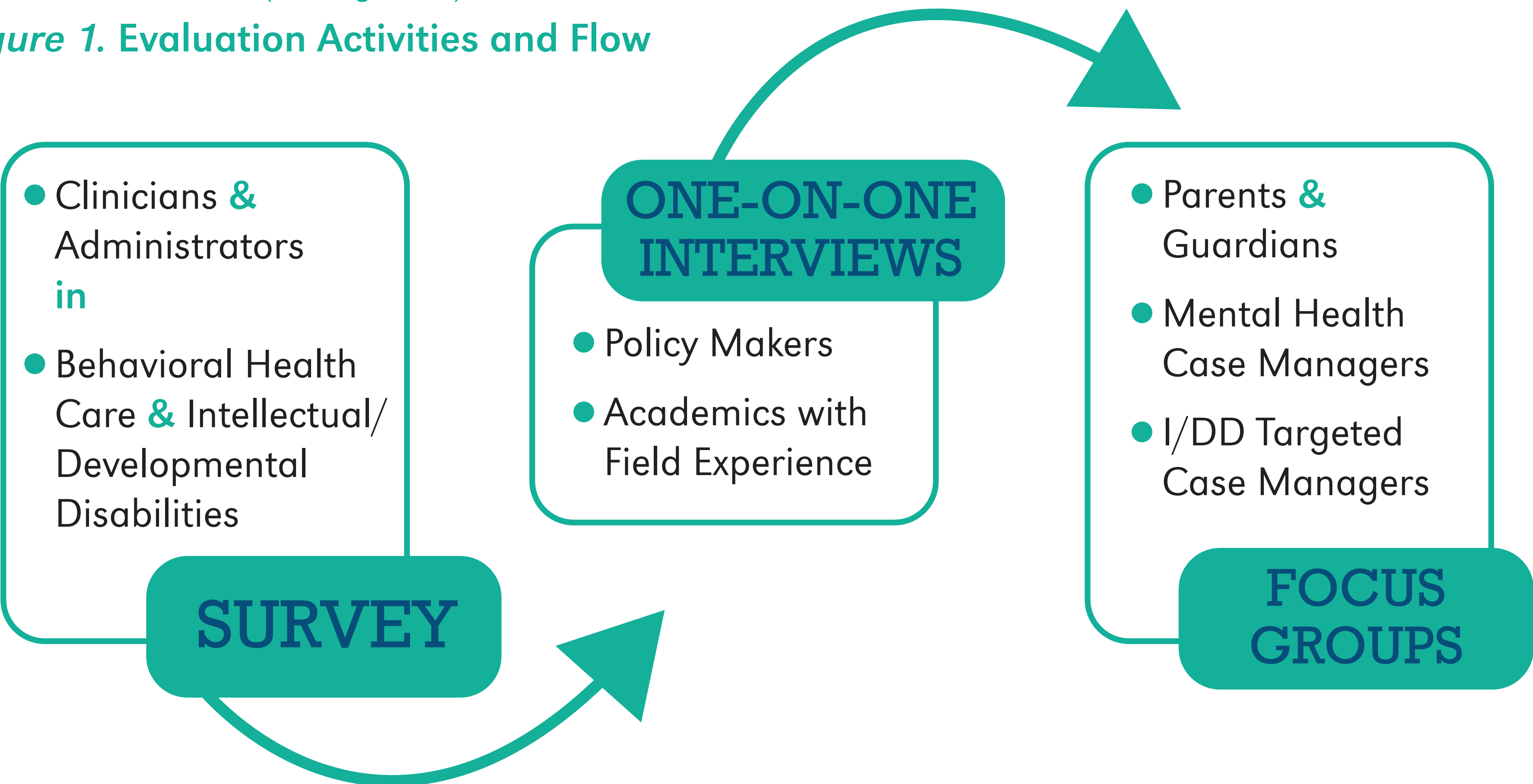
## RESEARCH GOAL

- Assess the services and gaps in Sedgwick County for persons with co-occurring behavioral health and developmental disability issues.

## METHODS

Evaluation Activities (see Figure 1)

Figure 1. Evaluation Activities and Flow

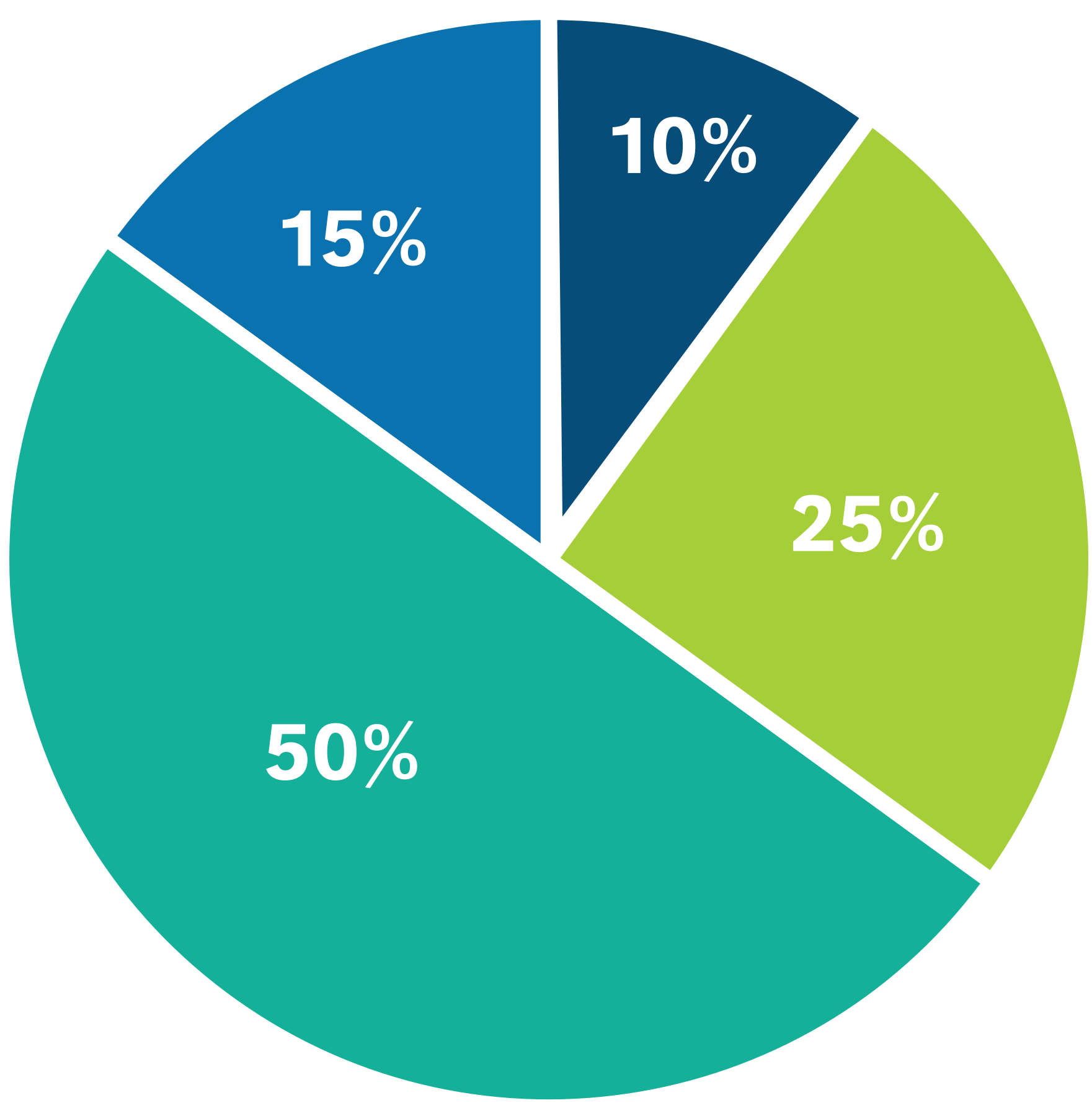


## METHODS (Cont.)

### Participants:

- Survey (n = 167) recruited behavioral health clinicians and administrators as well as I/DD clinicians and administrators. See Figure 2
- Interviews (n = 5) recruited two academics and three policy makers.
- Focus Groups (n = 36) recruited nine parents/guardians, 16 behavioral health case managers, and 11 I/DD targeted case managers and behavior specialists.

Figure 2. Evaluation Activities and Flow



I/DD Clinician - 10%

BH Administration - 25%

BH Clinician - 50%

I/DD Administration - 15%

## RESULTS

Participants across all methods mentioned the need for better training & collaboration and the removal of the barriers that currently prevent or discourage cross-discipline cooperation in order to improve the system. Table 1 outlines key barriers to serving those with co-occurring disorders.

Table 1. Barriers

### Overall 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)

Only 38% of behavioral health providers adjusted their diagnostic and treatment decisions for clients with I/DD by using the DM-ID and only 22% reported using it often or all the time.

Policy makers noted specific systemic issues that affect this population in particular:

- Limitations on where and how services occur
- Duplication of assessments
- Differences in waiting list and cost of care policies



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## RESULTS (Cont.)

### Parent/Guardian input was particularly impactful:

- 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.

### Key statements from parents that highlight their concern:

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

## CONCLUSIONS & IMPLICATIONS

- The inclusion of the parents' voice was key to understanding the experience of this population.
- SCDDO utilized this research to ground their strategic planning. (This strategic plan is available at [www.sedgwickcounty.org/cddo/facts\\_and\\_details/SCDDOPriorities.pdf](http://www.sedgwickcounty.org/cddo/facts_and_details/SCDDOPriorities.pdf))
- An increase in cross-professional trainings and the creation of a new learning collaborative help to address some of the barriers uncovered in this study.
- The results of this study led to the planning and implementation of another study to try and understand the prevalence of trauma in the I/DD population which would have implications for how co-occurring disorders may affect more clients than previously estimated.