Crisis Care for Individuals with Intellectual and Developmental Disabilities

A NEEDS ASSESSMENT FOR THE GUILD FOR HUMAN SERVICES

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Agenda

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- Background
- Methodology
- Limitations
- Secondary Data
- Literature Review
- Internal Records
- Key Informant Interviews
- Possible Areas for Improvement
- Possible Programming
- Next Steps

Summary

- The Guild, state, and region have many strengths in supporting individuals with IDD in mental health crisis.
- Possible areas for improvement that the Guild may act on:
  - Training in trauma-informed care and positive behavior support.
  - Staff and clinical services during evening/overnight shifts.
  - Follow up to mental health crises at group homes.
  - Tracking data related to mental health crises.
- Possible programming options include:
  - Respite
  - CBAT
  - Long-term stabilization unit

Background

- The Guild provides educational, residential, and clinical programming for individuals with IDD.
- Serves a complex population:
  - 50% have formal mental health diagnosis.
  - More than 50% receive at least one psychotropic medication.
  - More than 80% have ASD.
  - About 1/3 do not have verbal ability.
- Have identified the need to improve care for individuals when they experience mental health crisis.

The Guild
FOR HUMAN SERVICES

Defining "Mental Health Crisis"

National Alliance on Mental Illness:

"Any situation in which a person's behavior puts them at risk of hurting themselves or others and/or prevents them from being able to care for themselves or function effectively in the community."[1]

- Examples:
  - Threats or acts to harm oneself or others
  - Inability to perform activities of daily living
  - Unpredictable mood swings
  - Aggressive behaviors
- Focus on crises that escalate to level of requiring external support.

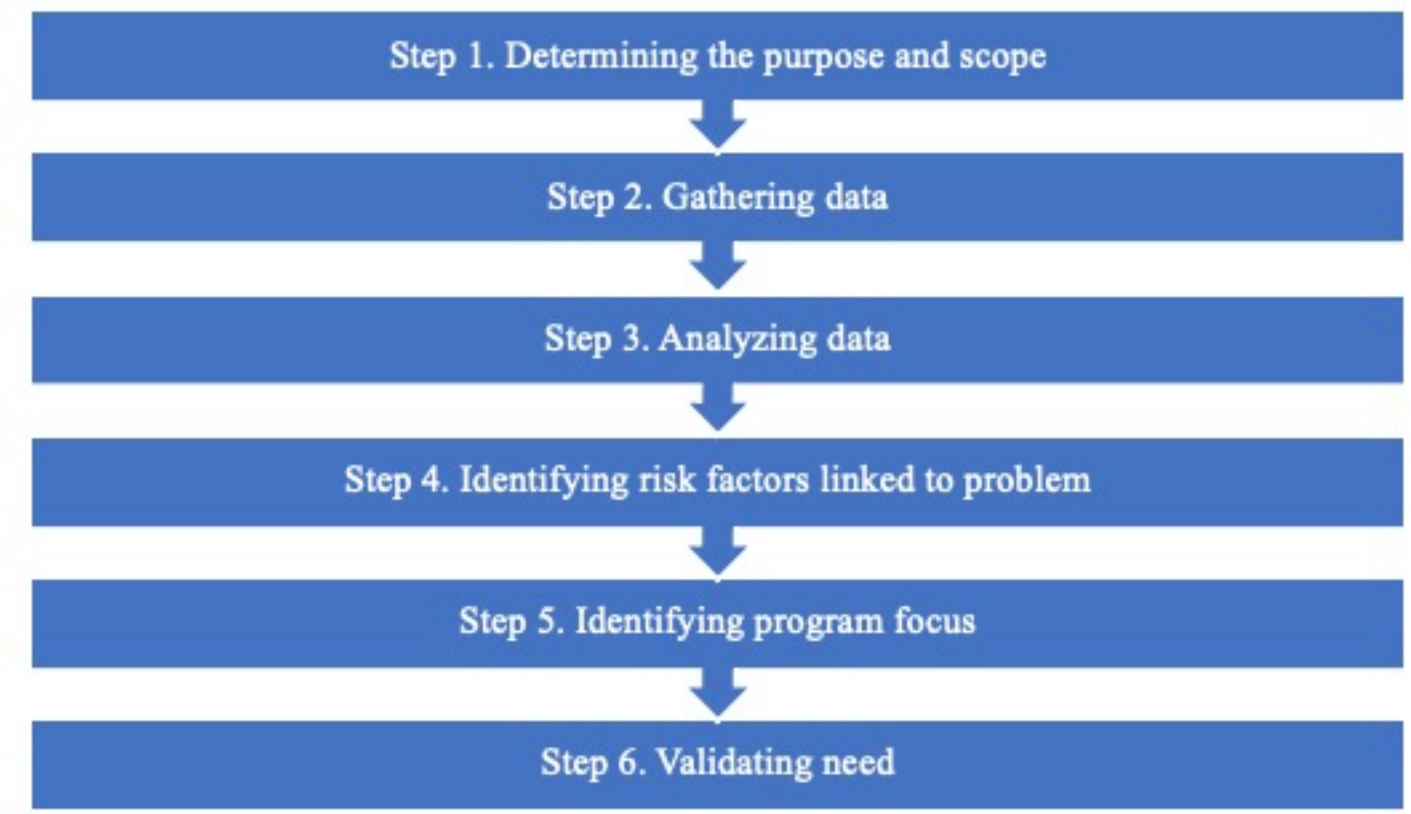
Needs Assessment

Objective:

Identify opportunities to improve care for individuals with IDD when they experience mental health crises by:

1. Initiating a needs assessment for a program to address Guild, state, and regional gaps in psychiatric services.
2. Developing a review of current models of care to identify best practices.

Methodology



Six-step process for conducting a needs assessment outlined by McKenzie, Neiger, and Thackeray.[2]

Data Collection

Limitations

- Needs assessment conducted during COVID-19 pandemic.
- Snowball approach to interviewing.
  - No students or residents
  - One parent
- Lack of internal data outside of admissions records.
- Limited secondary data and focus on ASD.

Secondary Data

- CDC: Prevalence of ASD is increasing.
  - 1 in 54 children in US identified with ASD.[3]
  - Prevalence of ASD increased by 6 to 15% each year from 2002-2010.[3]
  - 5.4 million adults aged 18-84 with ASD live in the US.[4]

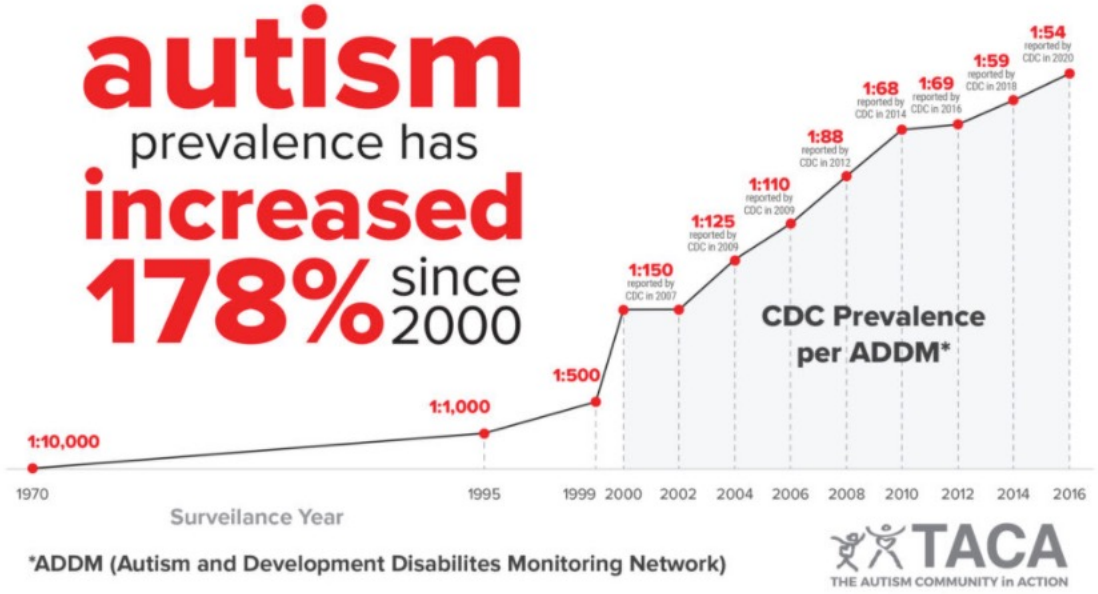


Image from: Autism Statistics & Cost. The Autism Community in Action (n.d.) Accessed March 24, 2021. https://tacanow.org/autism-statistics/

Secondary Data

- Mental illness is highly prevalent in individuals with ASD.[5-7]
  - 54 to 70% of individuals with ASD have co-occurring mental illness.
  - Most common diagnoses: ADHD, anxiety, depression, schizophrenia, and bipolar disorder.
  - Elevated rates of trauma and suicide.
- Leading cause of ED visits for Individuals with ASD is mental illness.[8]
  - Mass. 2012: 37.3% of individuals with ASD had at least one ED visit.[9]
- **However, mental health services for individuals with IDD remain extremely limited.**

Secondary Data

ED boarding:

"Practice of holding patients in the hospital ED for extended periods of time while evaluating the need for or finding a bed for hospital admission."[10]

- CMHC: Individuals with IDD are more likely to board, board for longer durations, and be subjected to seclusion and restraints.[10]
  - 87.2% board for 12 or more hours.
  - 38% board for more than 3 days.
  - 20% who were initially assessed to require inpatient or acute residential levels of care are discharged home with only outpatient services.

Literature Review

- There remains a limited, though growing, body of literature on interventions for youth and adults with IDD in mental health crisis.
- Studies support specialized programs for children and adolescents with IDD over general programs.
- Inconclusive for adults; however, **studies have demonstrated that general programs do not meet the needs of patients with IDD.**

Models of Care

- Specialized inpatient units
  - E.g. Bradley Hospital in Rhode Island, Hospital for Special Care in Connecticut, Spring Harbor Hospital in Maine.
- Crisis stabilization
  - Behavioral urgent care (e.g. Access Center at Bradley Hospital)
  - Community-based crisis intervention (e.g. START)
  - Therapeutic/emergency respite (e.g. Murdoch Developmental Center)
- Partial hospitalization programs
  - E.g. Neuropsychiatric Special Care Program at Children's Hospital Colorado

Common Themes among Models of Care

- *Programming*: multidisciplinary clinical teams, caregiver involvement, highly structured.
- *Environment*: single rooms, low-stimulating, clear visuals, multiple communication systems for patients who are non-verbal.
- *Staff*: high staff-to-patient ratios, extensive training in IDD
- *Funding*: insurance reimbursements, block grants

Internal Records

Total number of applications turned down	**179**
Number of applications screened out by admissions	**48**
-Number screened out due to severe community disruption	13
-Number screened out due to history of sexualized aggressions	9
-Number screened out due to severe pica	5
-Number screened out due to drug and/or alcohol abuse	3
Number of applications declined by clinical administrative team	**131**
-Number declined due to intensity of clinical or mental health condition	64
-Number declined due to history of bolting/elopement/running away	33
-Number declined due to high staffing needs	10
-Number declined due to age (about to turn 22)	6

Youth applications turned down between 1/2017-2/2021 due to mental health or behavioral needs.

Key Informant Interviews

- Exact frequency difficult for members to estimate due to sporadic nature of mental health crises.
- Overall agreement that:
  - Only small proportion of individuals experience crises, but those that do escalate frequently.
  - Adults typically experience less crisis than children and adolescents.
- Example two-month period (Nov. to Dec. 2020):
  - 2 out of 68 youth residents experienced mental health crises.
  - These 2 individuals went to ED 8 times combined.

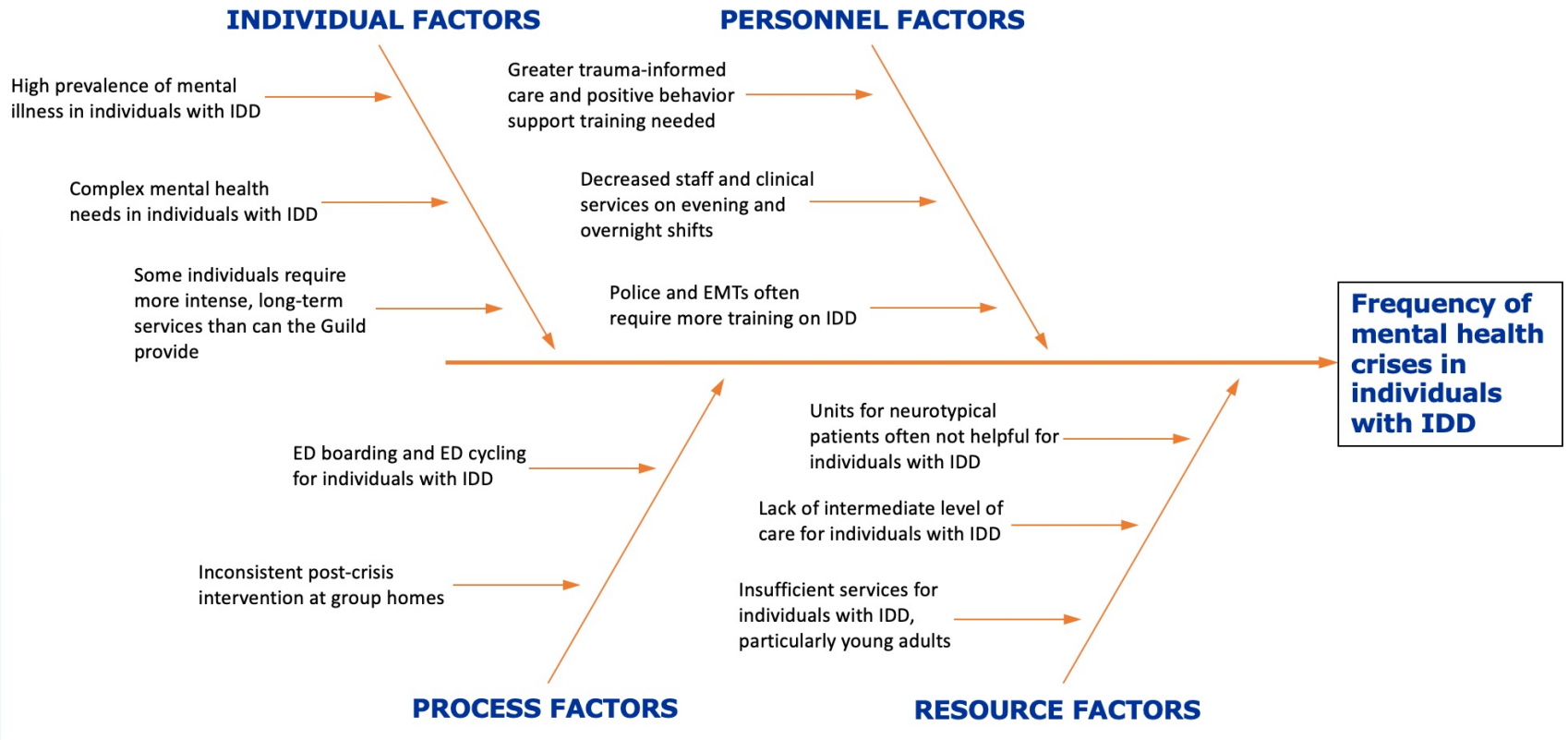
Strengths

- Guild:
  - Caring, dedicated staff that are committed to students and residents throughout mental health crisis.
  - Team-oriented culture that is close-knit and professionally diverse.
  - Strong, ABA-based programming and recently expanded clinical services that includes nursing, psychiatry, psychology, and therapy.
- Massachusetts:
  - Robust insurance coverage for ABA and other services.
  - MCI/ESP for individuals in mental health crisis.
- New England: Access to specialized inpatient units for individuals with IDD in neighboring states.

Gaps

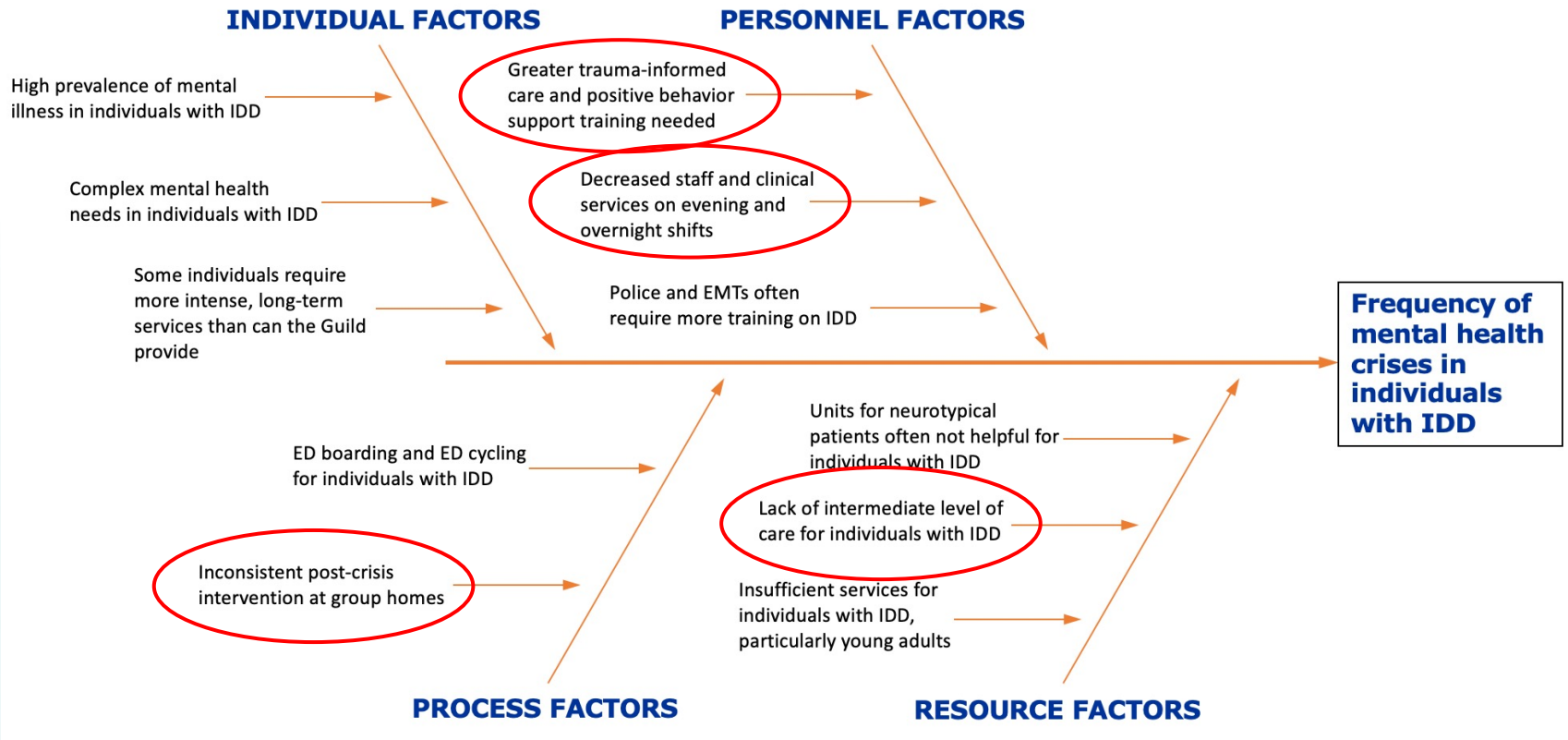
- Guild:
  - More training on trauma-informed care and positive behavior support.
  - Staffing and clinical services during the evening and overnight shifts.
  - Inconsistent post-crisis intervention when individuals return after crisis.
- Massachusetts:
  - Police and EMTs often untrained on how to interact with individuals with IDD.
  - Lack of intermediate level of care between group homes and inpatient units.
- New England: Difficulty accessing services for young adults with IDD.

Factors Contributing to Crisis



- A number of individual, personnel, process, and resource factors influence the frequency of mental health crises.

Possible Areas for Improvement



- Red circles indicate factors that the Guild may target in next steps.

Possible Target: Training

- The Guild has made positive steps toward improving training:
  - CPI training has decreased use of external resources.
  - Introduction to trauma-informed care.
- **Greater training may improve daily approach to challenging behaviors and prevent escalation of mental health crises.**
  - Interviewees noted inconsistency in applying principles of trauma-informed care.
  - Interviewees advocated for greater training in trauma-informed care and positive behavior support.

Possible Target: Evening and Overnight Shifts

- Majority of crises occur during evening/overnight shifts.
- Possible explanations:
  - Decreased number of staff.
  - Lack of clinical services overnight.
- Interviewees suggested re-thinking approach to these shifts.
- Possible suggestions included:
  - Increasing staffing.
  - **Introducing a call system for clinicians.**
  - Establishing relationships with external clinical response teams.

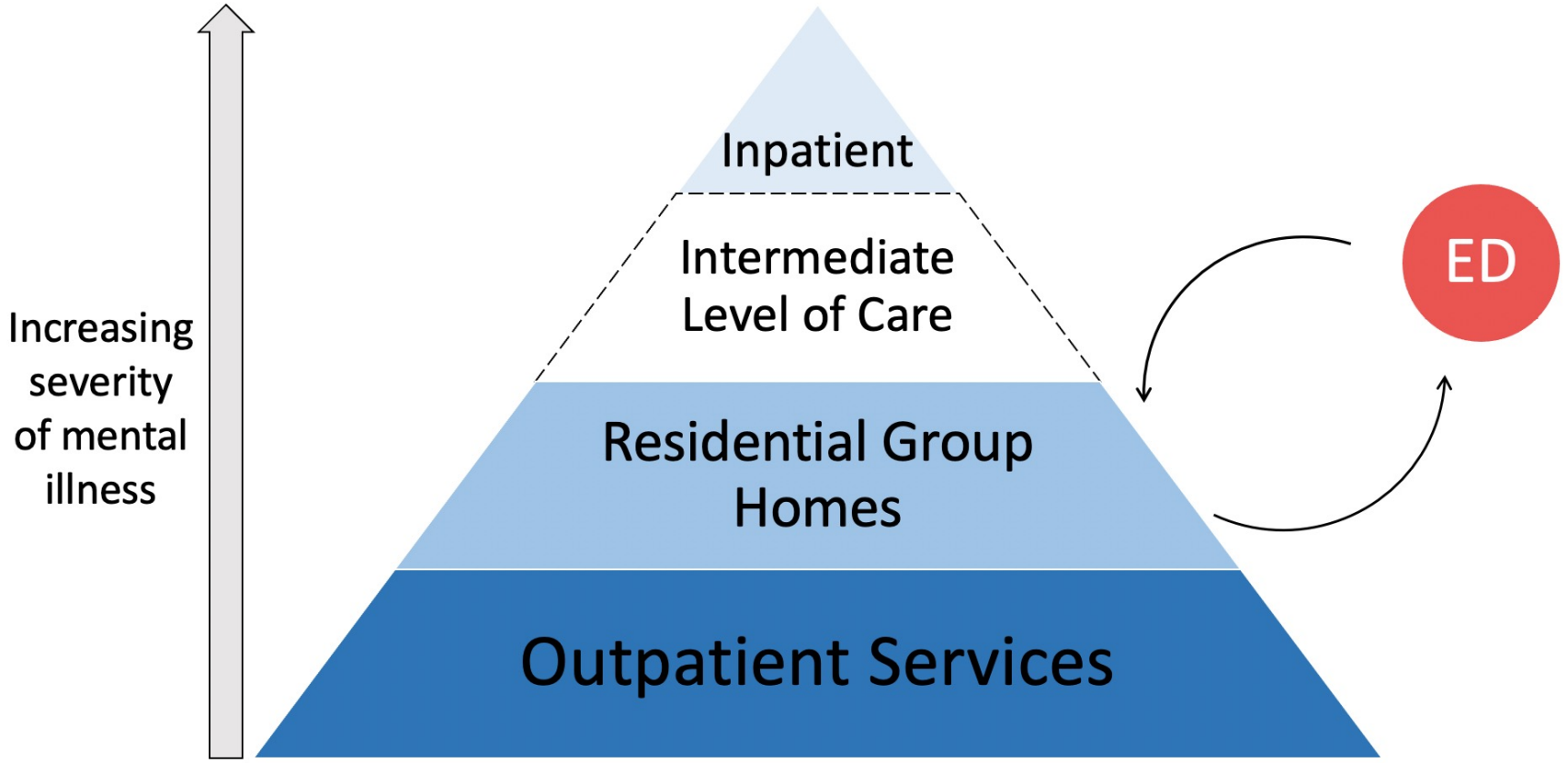
Possible Target: Post-Crisis Intervention

- Interviewees discussed inconsistent and incomplete follow-up to mental health crises.
- Post-crisis intervention should include:
  - The individual
  - Involved staff
  - Involved students and residents
  - Contributory factors in programming and environment
- **More comprehensive post-crisis interventions may reduce re-escalation of behaviors when individuals return from a crisis.**

Possible Target: Data Tracking

- Data related to mental health crises is not easily accessible.
- This data should be tracked to guide future improvement efforts.
- Possible indicators to monitor:
  - Number of individuals for whom staff needed to call for external support.
    - Number of times staff called the crisis team.
    - Number of times staff called 9-1-1.
  - Number of individuals who have had significant self-injury.
    - Number of times these individuals have had significant self-injury.
  - Number of individuals who have injured staff.
    - Number of staff injuries.
  - Number of individuals who have gone to the emergency room.
  - Number of individuals who have required inpatient hospitalization.
  - Number of individuals who need more intensive staffing.
  - Number of individuals who have required restraints.
  - Number of individuals who have damaged property.

Possible Programming



- An intermediate level of care is needed between residential group homes and inpatient units, which may be respite, CBAT, or a long-term stabilization unit.

Possible Programming: Respite

"We need respite care for both students and staff. We need to have a place that isn't the emergency room. A place and space to form a behavior plan, rule out medical problems, adjust medications, and have a psychiatrist and counselor… The reason why is to provide space for staff to assess what behaviors are the result of the kid and what is the result of staff. To be transparent, sometimes we need respite for staff… I believe it is OK to say, 'We cannot handle this. We need space to regroup and then come back to feel energized again.' We need a real acknowledgment that that's ok and it's not bad. But it's exhausting to handle big behaviors and potentially get hurt. Respite gives space to reconsider our programming and the student's behavior and how those intersect. Sometimes it's a little bit of both, the staff and the students. Sometimes it is because of us that behaviors happen. Because we are human. Respite gives space for us to minimize our impact on the behaviors."

– Guild leadership staff

Possible Programming: Respite

- Different approaches to respite exist:
  - Planned respite
  - Therapeutic/emergency respite
- Respite may provide time and space for group home staff to complete comprehensive post-crisis interventions.
- Interviewees emphasized how respite may benefit students, residents, *and* staff.

Possible Programming: CBAT

"This has been identified as a problem over and over and over again. There are no CBAT beds for kids with autism in the whole state… There is a large number of kids on the autism spectrum who are boarding, waiting, most of them, frankly, CBAT. If there was one. They're not awaiting CBAT because there isn't one… And they're there waiting for 30 days. I mean ridiculous. Ridiculous. That's every day… If one were to have a 12 to 16 bed CBAT, it would easily be full all the time with kids coming and going.

– Katherine Ginnis, Senior Director at MassHealth

Possible Programming: CBAT

- Currently available CBATs often provide no benefit for individuals with IDD in mental health crisis.
- CBAT would likely require:
  - Provider team similar to inpatient units (psychiatrists, BCBAs, social workers, speech therapists, occupational therapists, etc.)
  - Highly structured programming
- CBAT may work symbiotically with new inpatient unit being built at Cambridge Health Alliance.

Possible Programming: Long-Term Stabilization Unit

"[Hogan is] extremely effective. We had somebody who was so decompensated, at an all-time low. Experiencing delusions, hallucinations, paranoia, SI, throwing rocks at cars, running away. Ongoing challenges we were unable to manage. It got to the point where it was not safe. He went to Hogan where he was able to work on every aspect of his care. There, they are committed to stabilizing the person. Long-term, consistent improvement. He's been very stable since returning and using strategies implemented at Hogan… There's only so much we can do because we are a community-based residence. We're not a locked facility."

– Guild leadership staff

Possible Programming: Long-Term Stabilization Unit

- Interviewees advocated for a unit modeled after DDS Hogan Evaluation and Stabilization Unit.
- Features:
  - Large multidisciplinary team similar to inpatient unit.
  - Locked unit with lengths of stay ranging from months to years.
  - Long length of stay allows for significant medication changes and extensive therapy.
- Question of how long-term unit fits with Guild's philosophy and current approach.

Next Steps

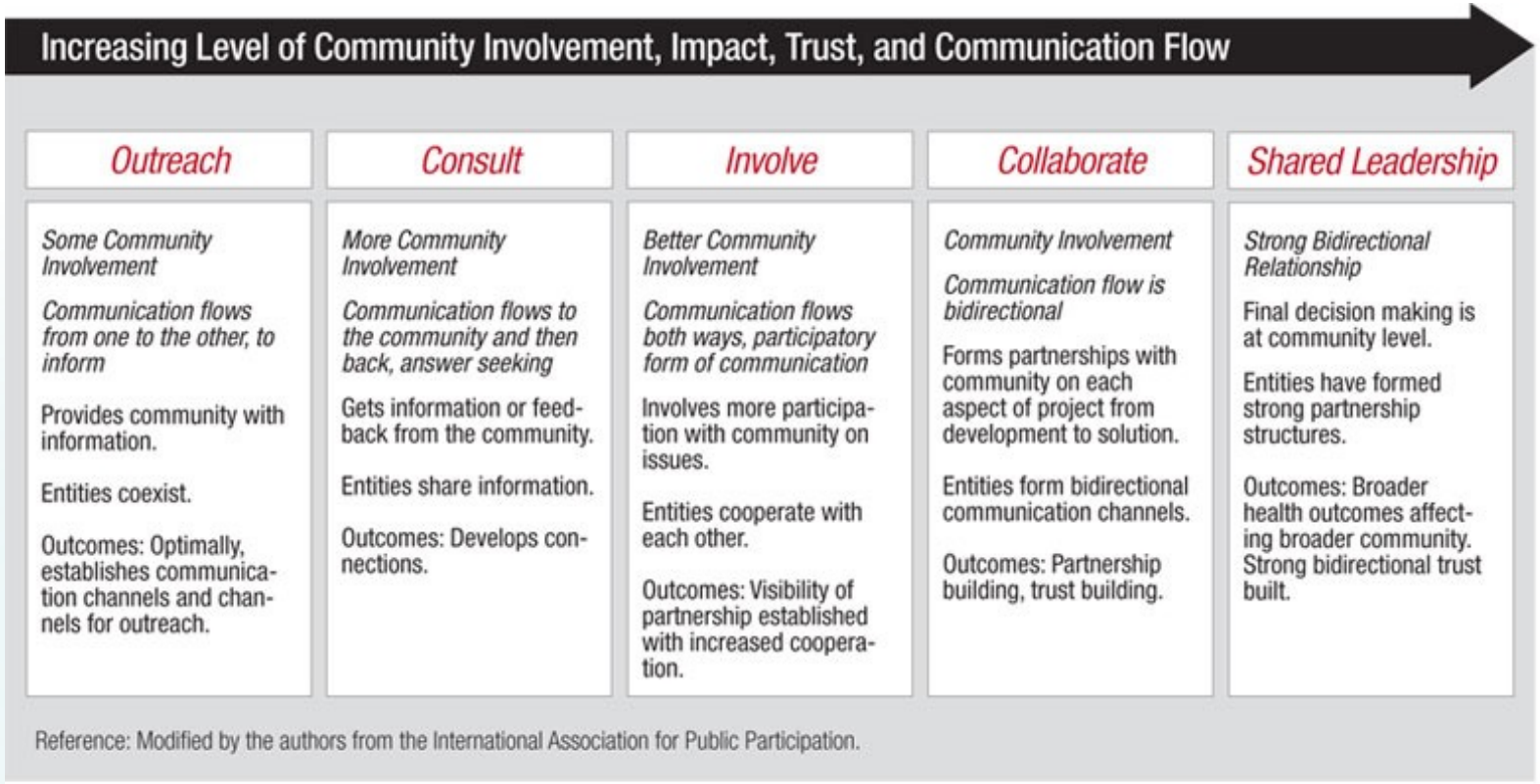


Figure 1.1. Community Engagement Continuum

Image from: Principles of Community Engagement – Second Edition. Agency for Toxic Substances and Disease Registry (2011) Accessed March 24, 2021. https://www.atsdr.cdc.gov/communityengagement/pce_what.html

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