



# Crisis Care for Individuals with Intellectual and Developmental Disabilities

A NEEDS ASSESSMENT FOR THE GUILD FOR HUMAN SERVICES

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## Executive Summary

### Background

The Guild for Human Services provides educational, residential, and clinical services to individuals with intellectual and developmental disabilities. Mental illness is a significant challenge in this population, and the Guild has recognized the need to improve care for these individuals when they experience mental health crises. Consequently, the Guild initiated this needs assessment to: 1) Identify current gaps in mental health services; 2) Explore models of care and best practices for this population.

### Methodology

This needs assessment utilized a mixed methods approach with both quantitative and qualitative data. The four sources of data came from secondary data sources, a literature review, internal records, and key informant interviews with Guild leadership, leading experts on IDD, a state partner, and a parent.

### Summary of Key Findings

- Key Finding 1: Diagnoses of intellectual and developmental disabilities are increasing in frequency, but the availability of specialized mental health services for this population remains limited.
- Key Finding 2: Emergency department boarding is a significant challenge for individuals with intellectual and developmental disabilities.
- Key Finding 3: A number of individual, personnel, process, and resource factors influence the frequency of mental health crises.
- Key Finding 4: An intermediate level of care is needed between residential group homes and inpatient units, which may be respite, community-based acute treatment, or a long-term stabilization unit.
- Key Finding 5: A significant number of youth with intellectual and developmental disabilities require more intensive long-term settings than the Guild can provide.
- Key Finding 6: Mental health services are especially limited for young adults (age 18-22) with intellectual and developmental disabilities as they age out of youth services.
- Key Finding 7: There is a growing body of research on effective models of care for individuals with IDD in mental health crisis. Common themes include an emphasis on multidisciplinary clinical teams, highly structured environments, and high staff-to-patient ratios with training in IDD.
- Key Finding 8: Data related to mental health crises at the Guild should be tracked.

## Background

### The Guild for Human Services

The Guild for Human Services was founded in 1952 as The Protestant Guild for the Blind. The Guild's focus changed over time to now serve individuals with intellectual and developmental disabilities (IDD) who have complex needs, such as dual diagnoses of autism spectrum disorder (ASD) and mental illness. Today, the Guild's mission is "to educate, encourage, and empower individuals with intellectual disabilities so they may achieve their full potential to lead high-quality lives and participate meaningfully in society."

The Guild serves approximately 140 individuals through educational, residential, and clinical programming, which includes a special education school, eight group homes for youth, and eleven group homes for adults. The Guild School serves students from age 6 to 22 with a curriculum dedicated to skill development in communication, sensory integration, positive behaviors, socialization, vocational support, and self-care. A multidisciplinary team of teachers, teaching assistants, and therapists work to assist each student to achieve their Individualized Education Plan goals. The residences are family-style homes that similarly foster greater independence in daily living with staff trained to address complex needs. Clinical services include a variety of mental health clinicians with residents provided individualized behavior support plans based on Applied Behavior Analysis (ABA) principles.<sup>1</sup>

### Context

The Guild's current mental health services include two consulting psychiatrists, a psychologist, Board Certified Behavior Analysts (BCBAs), nurses, mental health counselors, clinical social workers, and extensive behavioral and support staff. A significant proportion of the Guild's population has mental health needs. About 50% have a formal mental health diagnosis, though this is likely an underestimate due to challenges in diagnosing individuals with IDD. Additionally, more than 50% receive at least one psychotropic medication. Over 80% have ASD and about one-third are non-verbal, which further complicates treatment.

Given the frequency of mental health challenges, the Guild leadership has identified the need to strengthen mental health care for students and residents, particularly when they experience mental health crises. The Guild's leadership has also expressed the desire to develop greater research capacity given the significant knowledge gap in treating individuals with co-occurring IDD and mental illness.

As defined by the National Alliance on Mental Illness, a mental health crisis is "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."<sup>2</sup> Common signs of a mental health crisis include the inability to perform activities of daily living, unpredictable mood swings, aggressive behaviors, property destruction, and threats or acts to harm oneself or others. At the Guild, some mental health crises can be managed effectively internally. This report specifically focuses on crises that escalate to the level of requiring external support, such as 9-1-1 emergency services.

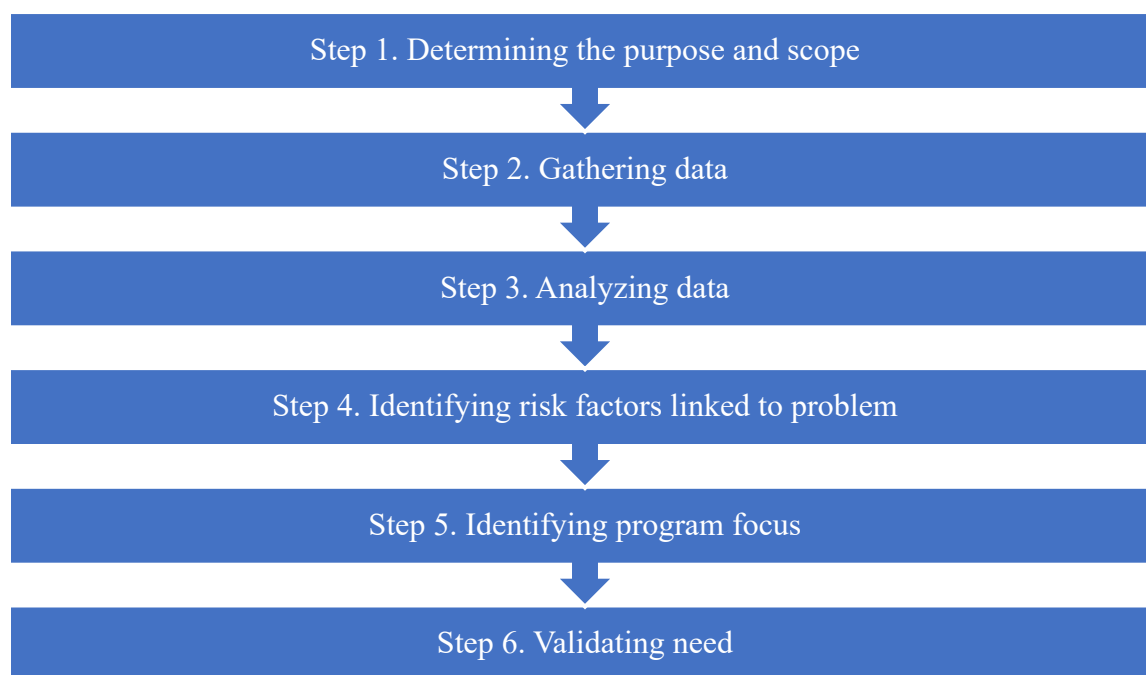
## Needs Assessment Purpose and Scope

The purpose of this report is to identify opportunities to improve care for individuals with IDD when they experience mental health crises. The primary objectives include:

1. Initiate a needs assessment for a program to address Guild, state, and regional gaps in psychiatric services for individuals with IDD experiencing mental health crises.
2. Develop a review of current models of care and identify best practices.

## Methodology

The needs assessment was conducted through the six-step process outlined in McKenzie, Neiger, and Thackeray (**Figure 1**).<sup>3</sup> The process includes: 1) Determining the purpose and scope of this project; 2) Gathering both primary and secondary data; 3) Analyzing the data; 4) Identifying risk factors linked to suboptimal crisis care; 5) Identifying models of care that programs may implement; and 6) Validating the need for these programs.



**Figure 1.** Six-step process for conducting needs assessment outlined by McKenzie, Neiger, and Thackeray.<sup>3</sup>

Step 1 involved defining the purpose and scope of this needs assessment with Guild Chief Executive Officer Amy C. Sousa and Chief Operating Officer Michael J. Clontz. The priority population was determined to be individuals with IDD, especially those who receive Guild services, though programming would ideally support state and regional gaps as well. Leadership had previously identified the need to improve crisis care for this population and commissioned an assessment of this public health challenge.

## Data Collection

The needs assessment sought to evaluate the current landscape of crisis care for individuals with IDD within the Guild, Massachusetts, and beyond. The following questions were decided to be in scope for this needs assessment and guided data collection efforts.

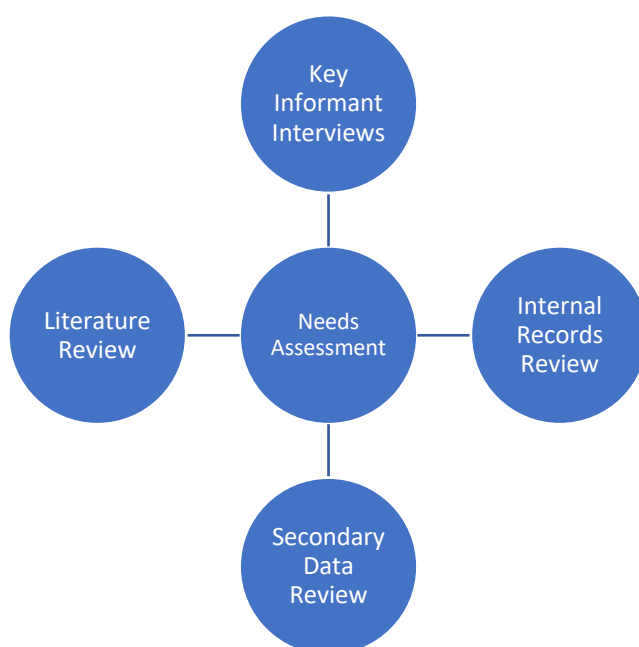
1. What are the current frequency and outcomes for individuals with IDD who experience mental health crises?
2. What are the strengths and weaknesses of the current system in caring for this population? What programs are available? What gaps still exist?
  - a. What age groups of this population have the greatest need?
  - b. What is currently being done to address these gaps?
3. What are protective factors and risk factors that influence outcomes for this population?
4. What interventions may improve the mental health outcomes of this population?
  - a. What evidence exists to support these interventions?
  - b. How may those interventions be implemented in this context?

To collect this data, a mixed methods approach with both qualitative and quantitative data was used (**Figure 2**). The approach centered on secondary data, a literature review, key informant interviews, and internal records.

- **Secondary sources** provided epidemiological data on IDD, particularly ASD, within Massachusetts. These data sources estimated the prevalence of mental health challenges in this population, in addition to pertinent risk factors and health care utilization rates.
- **Literature review** on the effectiveness of different models of care for individuals with IDD was conducted. Literature was identified by using the search terms “disability,” “autism,” “mental health,” and “acute” in PubMed and PsycINFO databases. Additional models of care were identified by entering the same search terms in Google.
- **Internal records** were reviewed to identify gaps in crisis care. Though the initial goal was to review individual patient records and collate systems-level data, the COVID-19 pandemic presented challenges to accessing this data. Instead, the admissions office provided referral data that gave insight into the Guild’s and state’s needs.
- **Key informant interviews** provided the opportunity to ask about individual beliefs about crisis care and discuss sensitive topics. A snowball approach was employed to identify stakeholders that could provide insight into the current system of care. From December 2020 to March 2021, thirteen semi-structured interviews were conducted over Zoom, a teleconferencing platform. Each interview was 30 to 60 minutes in duration. Interview guides were made for different groups, such as Guild leadership, parents, state partners, and leading IDD experts to explore their perceptions on the strengths and weaknesses of crisis care at the Guild and the state. Interview responses were then transcribed, coded, and analyzed using Dedoose qualitative data software. See **Appendix B** for a list of interviewees.

## Limitations

There are a number of significant limitations with this needs assessment design, many of which relate to the COVID-19 pandemic. First and foremost, while the snowball method of selecting informants allowed for key members of the Guild leadership to provide input, only one parent and no students or residents were interviewed. The pandemic precluded in-person interviews, and many of the students and residents have difficulty communicating over teleconference platforms. The pandemic also placed a disproportionate amount of strain on parents of children with IDD, which made scheduling interviews challenging. Second, during the needs assessment, the Guild relied on paper records, though it was in the process of transitioning to an electronic records system. Internal data such as the number of mental health crises, hospitalizations, and emergency department (ED) visits, among other crisis-related data, remained difficult to access. Third, the secondary sources have a time lag and may have varying definitions from one another. National and state data systems for IDD also remain extremely limited, with the vast majority focusing specifically on ASD.



**Figure 2.** The needs assessment design focused on four sources of data: key informant interviews, internal records review, secondary data review, and a literature review.

## Secondary Data Review

A review of secondary data sources about IDD revealed the scope of this public health challenge, though the vast majority of data available pertains specifically to ASD. Estimates from the Centers for Disease Control and Prevention (CDC) suggest that about 1 in 54 children in the United States are identified with ASD, and the prevalence of ASD has increased by 6 to 15 percent each year since 2002.<sup>4</sup> Another CDC study utilizing National Survey of Children's Health data estimates that about 5.4 million adults aged 18 to 84 years with ASD live in the United States. In Massachusetts, an estimated 2.42% of adults have ASD.<sup>5</sup>

Epidemiological studies suggest that 54 to 70% of individuals with ASD have co-occurring mental illness. The most common co-diagnoses include attention deficit and hyperactivity disorder, anxiety disorders, depression, schizophrenia, and bipolar disorder.<sup>6–8</sup> Recent literature also suggests elevated rates of exposure to trauma and suicide in this population compared to individuals without ASD. Despite these high prevalence rates, individuals with ASD are often undiagnosed and untreated for mental illness. Most assessments rely on clinical interviews, which is challenging for individuals with limited verbal abilities. Furthermore, clinicians with experience treating individuals with ASD are critical to distinguishing between ASD and psychiatric diagnoses. However, although rates of ASD diagnoses are rising, access to specialized mental health clinicians remains extremely limited.<sup>9</sup>

A consequence of this limited access to mental health care is ED boarding. ED boarding is defined as “the 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.”<sup>9</sup> Studies have noted that the leading cause of ED visits among individuals with ASD is mental illness.<sup>10–12</sup> According to data from the Agency for Healthcare Research and Quality, the number of people with ASD who were seen at an ED nearly doubled from 81,628 in 2009 to 159,517 in 2014.<sup>13</sup> In Massachusetts, MassHealth utilization data indicates that more than one out of three individuals (37.3%) with ASD had at least one ED visit in 2012.<sup>14</sup>

The Children’s Mental Health Campaign (CMHC) found that individuals with IDD are more likely to board in the ED, board for longer durations in the ED, and be subjected to seclusion and restraints in the ED than individuals without IDD.<sup>9</sup> A 2016 CMHC study showed that 13% of individuals who presented to the ED in psychiatric crisis had IDD. The most common presenting problems included aggressive, homicidal, or risk-taking behavior (60%) and self-injurious behavior, suicidal ideation, or suicide attempt (30%). About 87.2% of individuals with IDD boarded for 12 or more hours compared to 81.6% of individuals without IDD. Also, 38% of individuals with IDD boarded for more than three days. About 20% of individuals with IDD, compared to 14% of individuals without IDD, who were initially assessed to require inpatient or acute residential levels of care were discharged home with only outpatient services.<sup>15</sup>

Critically, the extent of ED boarding is typically highly seasonal. Children and adolescents without IDD present with psychiatric crisis at dramatically lower rates in the summer months of July and August. However, the incidence of psychiatric crisis and ED boarding in children and adolescents with IDD remains fairly consistent throughout the year regardless of season.<sup>15</sup>

## Literature Review

There remains a limited, though growing, body of literature on the effectiveness of dedicated units for youth and adults with IDD. Furthermore, of the studies that exist, the vast majority focus on inpatient units and are retrospective chart reviews that lack a control group.<sup>16</sup>

### Child and Adolescent Units

In the absence of definitive studies, specialized units for children and adolescents with IDD have been considered to provide higher standards of care than general units in expert opinion.<sup>17</sup>



Specialists express concerns that staff on general units lack the training and experience necessary to understand and respond to individuals with IDD and co-morbid psychopathology, leading to higher risk for inaccurate assessments and inappropriate uses of seclusion, restraints, and sedating medications. General units also may be unfamiliar and overstimulating for many neurodiverse patients, which can cause anxiety and exacerbate symptoms of distress such as self-injury or aggression.<sup>18</sup> Furthermore, individuals with IDD are vulnerable to exploitation by more able patients on general units.<sup>19</sup>

A growing body of research over the past decade has directly compared specialized and general inpatient units for children and adolescents with ASD. A 2012 study on the Neuropsychiatric Special Care program at Children's Hospital Colorado found that patients in the specialized program had reduced recidivism rates (12% vs. 33%) and decreased lengths of stay (26 days vs. 45 days) compared to a general inpatient unit. Another 2014 study on the Developmental Disorders Program at Spring Harbor Hospital in Maine similarly demonstrated that specialized units are associated with significant reductions in aggressive, self-injurious and tantrum behavior, and this improvement was sustained two months after discharge.<sup>20</sup>

A landmark prospective, multi-site study in 2018 by Pedersen et al. followed the outcomes of 350 youth with ASD admitted to six specialized units. The study is notable for its high proportion of minimally verbal patients with ASD who were resistant to prior treatments. The study found that these patients experienced significant reductions in serious problem behaviors from admission to discharge, and these reductions were sustained two months after discharge.<sup>21</sup>

In 2019, the first study to prospectively compare specialized and general units for youth with ASD was published. Overall, children treated in the specialized unit saw greater improvements in mental health than children treated in the general unit. This difference in treatment effects was sustained two months after discharge. Children discharged from the general unit also had higher frequencies of ED visits, psychiatric readmissions, crisis evaluations, and police contacts within two months of discharge, though only the difference in ED visits reached statistical significance. The differences in outcomes were most prominent for children with minimal verbal ability.<sup>22</sup>

Altogether, these studies provide preliminary support for specialized hospitalization programs for children and adolescents with IDD when compared to general inpatient units.

## Adult Units

The data for adult units is less conclusive than the evidence for child and adolescent units. A study published in 1999 of a specialized inpatient unit in Finland found that patients' psychiatric symptoms were significantly reduced both during the hospitalization and after discharge.<sup>23</sup> This study was limited by its small sample size of 40 patients, but was among the first prospectively designed studies on this topic. Another prospective study conducted in the United Kingdom in 2004 compared adults with IDD admitted to a specialized psychiatric unit with those admitted to a general psychiatric unit. The authors concluded that the specialized unit demonstrated greater improvements in mental health, though the specialized unit had longer lengths of stay on average.<sup>24</sup> This study was among the first to provide a direct comparison of specialized and general adult units with sample size of 39 patients in the specialized unit and 45 patients in the

general unit. Critically, the study was not a randomized intervention, and the authors note the selection bias in which patients were admitted to the different units.

A comprehensive 2004 review of the available literature suggested that there is no conclusive evidence favoring either general or specialized units for this patient population. Although specialized units were generally found to have better outcomes compared to general units, the research was often poor quality, lacked replication, and used inconsistent or inappropriate outcome measures.<sup>25</sup> However, an extension of this review published in 2009 ultimately concluded that, despite the lack of data for specialized units, studies have demonstrated that general psychiatric units do not sufficiently meet the needs of patients with IDD.<sup>26</sup>

## Models of Care

### *Specialized Inpatient Psychiatric Units*

A survey by Siegel et al. collected operational data from all eight specialized child and adolescent inpatient units in the United States that existed in 2012.<sup>27</sup> These units were located in Portsmouth, New Hampshire (two units); Providence, Rhode Island; Portland, Maine; Pittsburgh, Pennsylvania; Baltimore, Maryland (two units); and Streamwood, Illinois. The units served children and adolescents aged 4 to 21 years, with one unit occasionally accepting individuals up to 25 years old. There was a total of 137 specialized beds in the country, with an average unit size of 15.2 beds and a range of 9 to 22 beds. With the exclusion of an outlier, the average length of stay in the units was 30.75 days.

The units all emphasized multidisciplinary care with an average of 4.6 different clinical disciplines represented in each treatment team. All units employed a child psychiatrist, social worker, and either a psychologist or BCBA. More than 75% employed a special educator while only about one-third of the units employed a speech therapist or occupational therapist. Each unit also had high staff-to-patient ratios and averaged three direct care staff, such as technicians and nurses, for every four patients.

All units provided pharmacotherapy and behavioral modification therapy, two-thirds administered family therapy and sensory-oriented therapies, and less than half used individual psychotherapy, speech therapy, or occupational therapy. The most common reason for admission was aggression, followed by self-injurious behavior, property destruction, tantrums, decreased functioning, elopement, and sexualization. All units reported their greatest challenge was obtaining adequate follow-up services after discharge, followed by difficulties with funding, maintaining adequate staffing, staff injuries, intra-program communication, and hiring clinicians with expertise in this sub-specialty field.

Large differences were seen in how these units were funded. Some units were 90% funded by public health insurance while another unit was 90% funded by commercial health insurance. On average, 58.9% of funding came through public insurance and 38.9% came through commercial insurance with limited out-of-pocket payments. A more detailed list of select inpatient units that have published relevant information can be found in Table 1.

Table 1. Specialized inpatient units that have published service and environment details.

<b>Program</b>	<b>Location</b>	<b>Services</b>	<b>Environment</b>
Foundations Behavioral Health: Autism and Neurodevelopmental Inpatient Hospital <sup>28</sup>	Doylestown, Pennsylvania	<ul style="list-style-type: none"> <li>• Medication management with 24-hour nursing care and support services as described in each patient's Individualized Education Plan.</li> <li>• Emphasis on family-centered approach to treatment with Family Sessions and Family Education Days to enhance understanding of mental health issues and teach evidence-based practices.</li> <li>• Specialized de-escalation training for all staff members.</li> <li>• Group and individual expressive therapy, recreation therapy, and daily living skills instruction.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients aged 5 and older.</li> <li>• Structured programming with a focus on consistent routines and visual schedules.</li> <li>• Individualized communication systems such as sign language or Picture Exchange Communication Systems.</li> <li>• Posted graphic representations of target behaviors.</li> </ul>
Sheppard Pratt: Intellectual Disabilities and Autism Unit <sup>29</sup>	Baltimore, Maryland	<ul style="list-style-type: none"> <li>• Each patient receives a behavior plan designed by a behavioral specialist.</li> <li>• Each patient receives an activity plan created by an occupational therapist.</li> <li>• Many patients work one-on-one with an aide throughout their stay, which averages 10 days.</li> <li>• Group and individual sessions focused on creative expression, stress management, music, and social and leisure skills.</li> </ul>	<ul style="list-style-type: none"> <li>• 7 beds.</li> <li>• Patients aged 18 and older.</li> <li>• Sensory room with calming items to help stabilize patients in a safe, comforting environment.</li> </ul>
Autism Inpatient Unit at Hospital for Special Care <sup>30</sup>	New Britain, Connecticut	<ul style="list-style-type: none"> <li>• Program focuses on behavior strategy development, medication management, parent education, and discharge planning.</li> <li>• Parent education includes Intensive Parent Training program to assist caregivers practice behavior management in safety of the unit.</li> <li>• To reduce recidivism, the program conducts robust follow up and coordinates with caregivers and providers. The program administers a questionnaire a week after discharge and makes status calls with each child 30, 60, and 180 days after discharge.</li> </ul>	<ul style="list-style-type: none"> <li>• 8 beds.</li> <li>• Patients aged 10 to 21.</li> <li>• Highly structured day with educational activities.</li> <li>• Outdoor recreation area.</li> </ul>

Spring Harbor Hospital Developmental Disorders Unit <sup>16</sup>	Portland, Maine	<ul style="list-style-type: none"> <li>• Treatment is highly individualized with treatment modalities including applied behavior analysis, psychopharmacology, speech and occupational therapy, special education, family therapy, and parent behavioral management training.</li> <li>• Primary caregiver involvement is crucial to the treatment plan. Parents are offered a three-step behavior management training program where they learn the behavior plan, shadow staff running the plan, and ultimately try the plan themselves with staff supervision and coaching.</li> <li>• The readmission rate within one year is less than 10%.</li> </ul>	<ul style="list-style-type: none"> <li>• 12 beds.</li> <li>• Patients aged 5 to 21.</li> <li>• The program runs its own six-hour school day, and the school is often used as a place to try new interventions or behavioral plans.</li> </ul>
Five inpatient units dedicated for patients with IDD with mental health needs <sup>31</sup>	Ontario, Canada	<ul style="list-style-type: none"> <li>• Programs all offer medication management and individual behavioral therapy.</li> </ul>	<ul style="list-style-type: none"> <li>• Range from 15 to 29 beds.</li> <li>• Three of the units serve patients aged 16 and older. Two of the units serve patients aged 18 and older.</li> <li>• Units have quiet rooms to help stabilize patients.</li> </ul>
Fuller Hospital Intellectual Disabilities Unit <sup>32</sup>	Attleboro, Massachusetts	<ul style="list-style-type: none"> <li>• Provides individual behavior assessments and treatment planning.</li> <li>• Program coordinates with Department of Developmental Services to plan intake and discharge with the goal of enabling patients to return to community living.</li> </ul>	<ul style="list-style-type: none"> <li>• Patients aged 18 and older.</li> </ul>
National Autism Unit at Bethlem Royal Hospital <sup>33,34</sup>	Beckenham, United Kingdom	<ul style="list-style-type: none"> <li>• Provides neuropsychological assessment, individual and group psychotherapy, cognitive behavioral therapy adapted for ASD, occupational therapy, and other treatment modalities.</li> </ul>	<ul style="list-style-type: none"> <li>• 15 beds.</li> <li>• Patients aged 18 to 65.</li> <li>• Male-only unit.</li> <li>• Structured day with adult education, computing, aikido, relaxation, gardening, physical exercise, and voluntary work.</li> </ul>
University of Massachusetts Pediatric Emergency Mental Health Unit <sup>9</sup>	Worcester, Massachusetts	<ul style="list-style-type: none"> <li>• For cases in need of a specialty inpatient unit, children are retained in this ED for 96 hours to preserve priority on waitlists, then discharged with outpatient supports as they await admission.</li> </ul>	<ul style="list-style-type: none"> <li>• A single bed within the emergency unit that can be used as a “mini-inpatient unit” to change medications and stabilize a child for five days before being discharged home. This bed is reserved for children who cannot wait at home for an inpatient bed.</li> </ul>

### *Crisis Stabilization Centers*

There are a number of crisis stabilization centers across the United States dedicated for individuals with IDD. These centers vary widely in terms of their approach and services provided. Two featured models, the Crisis Response Center and the Access Center at Bradley Hospital, function like urgent care for behavioral health: patients receive immediate assessment and treatment before being observed and triaged to the appropriate level of care. In contrast, the Systematic, Therapeutic, Assessment, Resource, and Treatment (START) model focuses on community-based intervention while the Murdoch Developmental Center provides respite services to manage mental health crises.

Similar to therapeutic respite, community-based acute treatment (CBAT) provides short-term crisis stabilization for children and adolescents in mental health crisis. Patients are admitted to CBATs either directly from the community or as a step-down from an inpatient stay. They are unlocked 24-hour treatment settings with the goal of transitioning patients back to their respective communities. Interventions often include psychiatric assessment and treatment; pharmacological assessment and treatment; individual, group, and family therapy; mental health crisis and safety planning; and care coordination.<sup>35</sup> CBATs are primarily located in Massachusetts, though no dedicated units for children or adolescents with IDD exist. This literature review did not find peer-reviewed literature on the effectiveness of CBATs in managing mental health crises.

#### **Featured Model 1: Crisis Response Center**<sup>9,36</sup>

The Crisis Response Center at Tucson, Arizona operates similar to urgent care by providing walk-in, immediate treatment of behavioral health conditions, though it is not specialized for individuals with IDD. The unit provides rapid assessment within 45 minutes of intake to all patients brought in by police, ambulance, parents, schools, or others and has the capacity to medically clear patients with physicians and lab tests.

The unit is configured in a flexible manner to allow for large swings in patient traffic, with both youth and adult areas adding up to 10 crisis stabilization beds. The beds provide observation for up to 23 hours and are located directly across from the nurses' stations. If patients require care beyond 23 hours, they are moved upstairs to a 15-bed short-term sub-acute treatment area that provides intensive treatment for three to five days.

The Center is unique in its ability to intake a diverse range of patients, both youth and adults, and medically clear them for psychiatric stabilization. Additionally, the Center has a direct physical connection with a short-term unit.

#### **Featured Model 2: Access Center at Bradley Hospital**<sup>9,37,38</sup>

The Access Center at Bradley Hospital in Providence, Rhode Island, similar to the Crisis Response Center, provides immediate walk-in treatment for individuals with IDD. Critically, the unit is physically connected to multiple levels of behavioral health care, such as an outpatient crisis clinic, inpatient care, and a partial hospitalization program. The outpatient crisis clinic addresses urgent behavioral health needs that do not require hospitalization, but do require intervention within 48 hours.

Trained clinicians triage and evaluate children and adolescents, diverting a significant number away from EDs. Patients who require partial hospitalization or full inpatient care are organized by age and developmental ability. Both programs offer a structured, low-stimulation environment with ABA expertise, medication management, and individual therapy.

**Featured Model 3: START Model**<sup>9,39</sup>

The START model is an evidence-based approach to community-based crisis intervention for individuals with IDD. START emphasizes comprehensive support to optimize independence, treatment, and community living. A key step in the model is the development of a Cross-Systems Crisis Prevention and Intervention Plan, which the START clinical team creates with the members of an individual's support team. This is "an individualized, person-specific written plan of response that provides a clear, concrete, and realistic set of supportive interventions that prevents, deescalates, and protects an individual from experiencing a behavioral health crisis." The plan is strengths-based, proactive, and designed to be used across a variety of settings including a person's home, school, and community. The START clinical team remains engaged with a person's care after the immediate crisis has passed, providing specialized training, clinical expertise, and systems evaluations.

The model also includes respite services at designated START Resource Centers. For example, in New Hampshire, the START Resource Center provides stays up to 5 days for planned respite and up to 30 days for emergency respite. These centers provide a safe, therapeutic environment for crisis prevention and stabilization.

START has been identified as a model program by the US Surgeon General's Report and as a best practice by the National Academy of Sciences Institute of Medicine. The model has now been implemented in 15 states. START has shown to significantly reduce participants' behavioral challenges and improve their mental health. Additionally, START has demonstrated effectiveness in dramatically decreasing utilization of emergency services and inpatient hospital units, in some settings by as much as 40%. The gains made by START are remarkable given the limited evidence for many other crisis intervention programs.

**Featured Model 4: Murdoch Developmental Center**<sup>40</sup>

The Murdoch Developmental Center in Butner, North Carolina provides therapeutic respite to children and adolescents with IDD in mental health crisis. The program was specifically designed to divert individuals from EDs and inpatient psychiatric units. Therapeutic respite utilizes an ABA approach with the goal of stabilizing individuals to return to the community. The program also provides multidisciplinary, structured programming during the day, in addition to 24-hour staff coverage for safety. A core component of the respite program is careful discharge planning around the patients' reintegration into their communities to ensure continuity of care. The program offers respite stays between 3 to 45 days.

*Partial Hospitalization Programs*

Like crisis stabilization units, there are a few partial hospitalization programs dedicated for patients with IDD, though details and published data on their effectiveness are scarce. The most notable program is the Neuropsychiatric Special Care Program at Children's Hospital Colorado.

**Featured Model 5: Neuropsychiatric Special Care Program at Children's Hospital Colorado**<sup>16,18</sup>

This unit in Aurora, Colorado serves children and adolescents with ASD aged 4 to 17 years. Uniquely, it provides both short-term inpatient services (3 beds) and a partial program (up to 8 patients). The partial component was developed to decrease long inpatient stays and repeat admissions by allowing patients to leave the inpatient unit once stabilized while continuing treatment as a partial patient.

Staff includes psychiatrists, psychologists, behavior analysts, social workers, mental health counselors, nurses, an occupational therapist, speech therapist, creative arts therapists, and a consulting pediatrician. The staff ratio is maintained at 1:1 for inpatients and 1:2 for partial patients. Staff are trained in the Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH) model. For example, for error correction techniques, staff are trained to ask patients to "Try again" and demonstrate the appropriate behavior. Staff also provide social praise for appropriate behaviors to increase patient motivation.



Caregiver education is an essential component of the program as staff teach caregivers about behavior management and intervention. Caregivers are coached as they interact with the patients in the therapeutic milieu and receive regular feedback and instruction in weekly topic-specific groups.

The program emphasizes the visual strengths of the ASD population in a highly structured environment. There are predictable routines and visual cues, specific to individuals' needs and ability level, to guide patients on unit expectations and rules. For example, these visual cues include objects, pictures, and written word cues. The unit posts daily picture schedules and visual road maps to assist patients in understanding their choices and the outcomes of their behaviors. Furthermore, the environment is divided into different areas for groups, independent leisure, relaxation, and other activities to promote predictability and lessen the need for prompting since patients can associate activities with the different areas.

## Internal Records Review

An internal records review was planned to determine the frequency of mental health crises and related outcomes. The COVID-19 pandemic precluded access to the incident reports, which are kept on paper. The Guild is also currently transitioning to an electronic records system. Consequently, retrieving this data was not possible during this needs assessment.

The Guild admissions team provided data on the number of youth applications that were turned down from January 2017 to February 2021 due to mental health and behavioral needs. A total of 179 applications were turned down in this time period, with 48 screened out by the admissions team and 131 declined after review by the clinical administrative team. The most common reasons for screening out were severe community disruption, history of sexualized aggressions, severe pica, and drug and/or alcohol abuse. The most common reasons for being declined by the clinical administrative team include the intensity of an individual's clinical or mental health condition (e.g. homicidal ideation, suicidal ideation, past suicide attempts, and self-injurious behavior), a history of bolting/elopement/running away, high staffing needs, and age. A summary of these records is detailed in Table 2.

This data strongly suggests that a significant number of youth in the Department of Children and Families (DCF) system require a more intensive long-term setting than the Guild can provide, with greater clinical services and higher staffing ratios. This data also underscores the need for more long-term settings that can be responsive to individuals with histories of bolting, as well as settings for young adults who are between the ages of 18 and 22.

Table 2. Youth applications turned down from 1/2017 to 2/2021 due to mental health and behavioral needs.

<b>Total number of applications turned down</b>	<b>179</b>
<b>Number of applications screened out by admissions</b>	<b>48</b>
-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
<b>Number of applications declined by clinical administrative team</b>	<b>131</b>
-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

## Key Informant Interviews

Thematic content analysis of the key informant interviews revealed both strengths and weaknesses that the Guild, Massachusetts, and New England have in supporting individuals with IDD in mental health crisis. In addition, interviewees provided their expertise on possible programming for this public health challenge. Table 3 provides an overview of the strengths, weaknesses, and possible programming elicited from these interviews.

Table 3. Strengths, weaknesses, and possible programming for the Guild, Massachusetts, and New England.

<b>Strengths</b>	<ul style="list-style-type: none"> <li>• <u>Guild</u>: Caring, dedicated staff that are committed to students and residents throughout mental health crisis.</li> <li>• <u>Guild</u>: Strong, ABA-based programming and recently expanded clinical services that includes nursing, psychiatry, psychology, and therapy.</li> <li>• <u>Massachusetts</u>: Robust insurance coverage for ABA and other services.</li> <li>• <u>Massachusetts</u>: Mobile crisis intervention (MCI) / Emergency Services Program (ESP) for individuals in mental health crisis.</li> <li>• <u>New England</u>: Access to specialized inpatient units for individuals with IDD in neighboring states.</li> </ul>
<b>Weaknesses</b>	<ul style="list-style-type: none"> <li>• <u>Guild</u>: More training needed on trauma-informed care and positive behavior support.</li> <li>• <u>Guild</u>: Decreased staffing and clinical services during the evening and overnight shifts.</li> <li>• <u>Guild</u>: Inconsistent post-crisis intervention when individuals return after crisis.</li> <li>• <u>Massachusetts</u>: Police and emergency medical technicians (EMTs) often untrained on how to interact with individuals with IDD.</li> <li>• <u>Massachusetts</u>: Lack of intermediate level of care between group homes and inpatient units.</li> <li>• <u>New England</u>: Difficulty accessing services for young adults with IDD.</li> </ul>
<b>Possible programming</b>	<ul style="list-style-type: none"> <li>• Respite</li> <li>• CBAT</li> <li>• Long-term stabilization unit</li> </ul>

## Frequency

The Guild leadership staff had difficulty estimating the frequency of mental health crises because of their sporadic timing. At a given time, no individuals at the Guild may be experiencing crisis; at other times, up to three individuals may be experiencing crisis. Overall, however, most interviewees agreed that the adults typically experience less crisis than the children and adolescents. Most interviewees also agreed that only a small proportion of individuals experience crisis, but those that do escalate behaviors frequently. For example, in November to December 2020, two youth residents (out of 68 youth residents total) went to the ED a total of eight times. A closer review of the Guild's internal records is needed to establish the exact frequency of mental health crisis among students and residents.



## Strengths

### *The Guild for Human Services*

- *Staff:* Several interviewees acknowledged the difficult work that Guild staff do at the school and group homes, particularly when they encounter mental health crises. On a daily basis, staff conduct themselves professionally while supporting individuals who may have behaviors that are challenging. In light of this, interviewees noted the commitment of the staff in caring for Guild individuals. The parent interviewee in particular was impressed with the caring nature of the staff.

*“We’re very committed to staying with students throughout the crisis and still staff them throughout the emergency room and even the ambulance ride.” – Guild leadership staff*

- *Team-oriented culture:* Many members of the Guild leadership staff commented that the Guild believes strongly in teams. Leadership staff felt the Guild is close-knit and collaborative, such that members feel comfortable reaching out to others for support. Additionally, the teams are well-rounded and multidisciplinary, with members coming from a diversity of professional backgrounds. This team-oriented culture and professional diversity has been crucial to the Guild’s ability to effectively expand its services to now provide residential living for adults with IDD.
- *Growing clinical services:* In response to the increasing complexity of mental illness in Guild students and residents, the Guild has invested heavily in clinical services and ABA-based programming. Over the past decade, the Guild has added a Director of Mental Health Services, expanded nursing from 2 to 8.5 full-time employees, contracted two psychiatrists with expertise in IDD to visit patients weekly, and now has 8 full-time mental health clinicians who are licensed mental health counselors or licensed clinical social workers. So, during the day, many clinical services are available for both youth and adults.

### *Massachusetts*

- *Insurance coverage:* Compared to many other states, Massachusetts has robust insurance coverage for children with IDD. Massachusetts requires both commercial and public insurance programs to fully cover ABA, the primary treatment modality for children with ASD. The Department of Developmental Services (DDS) also provides an Autism Waiver Program for children up to eight years old to receive intensive in-home services, expanded habilitation, and education.
- *Clinical consultation for mobile crisis:* Massachusetts has MCI/ESP to support individuals experiencing mental health crisis. Individuals may call MCI/ESP to receive assessment, intervention, and stabilization services from a team of clinicians that travel to the location of the crisis. These programs are available 24 hours a day throughout the year. Notably, within the past year, Massachusetts has created a system for MCI/ESP clinicians to consult a

provider with expertise in ASD. The goal of this system is to improve MCI/ESP's effectiveness in supporting individuals with ASD when they experience mental health crisis.

### *New England*

- Though Massachusetts does not have any specialized inpatient psychiatric units for children and adolescents with IDD, patients from Massachusetts have been admitted to specialized units in neighboring states. For example, Hampstead Hospital in New Hampshire, Bradley Hospital in Rhode Island, Hospital for Special Care in Connecticut, and Spring Harbor Hospital in Maine have previously taken Massachusetts patients. Due to the COVID-19 pandemic, admissions across state lines have been difficult over the past year; however, Cambridge Health Alliance currently plans to add specialized ASD/IDD psychiatric beds to its Somerville campus and establish a new center dedicated to the treatment of youth with IDD.<sup>41</sup>

*"There are specialized acute hospitals like Hampstead, Bradley, Hospital for Special Care, and Maine. In many regions, these don't exist at all... There are also strong residential programs in the area." – External expert on IDD*

### **Weaknesses**

#### *The Guild for Human Services*

- *Training:* The Guild has improved training for staff in recent years to good effect. The 16-hour Crisis Prevention Institute (CPI) training has noticeably decreased the Guild's use of external resources during mental health crises. Additionally, all staff have been introduced to the basic principles of trauma-informed care. However, interviewees have noted inconsistency in applying these principles when working with students and residents. Consequently, interviewees advocated for greater training on trauma-informed care and positive behavior support. Interviewees believed that regular, ongoing training may help staff incorporate the core components of trauma-informed care and positive behavior support into their daily approach to students and residents, which would likely prevent the escalation of some mental health crises.

*"You need quality IDD-oriented training and experience... If you don't have the staff who understand positive behavior support, it breeds crisis and breeds externalizing behaviors. So, you really need staff who 'gets it' so to speak. That is the most important thing at all levels: nursing, medical staff, behavioral staff, and even administrative staff. Quality IDD-oriented training and experience." – External expert on IDD*

*"Within the Guild, we need to do a better job of initial training and ongoing training of staff members and how they can respond to incidents. We need more skills with verbal de-escalation, posture, and approach to work. It can't be a one-time training. It must be a system that's ongoing." – Guild leadership staff*

*“We need to have better responses to big behaviors through a trauma-informed lens. Trauma-informed means approaching individuals with a lens of, ‘My role right now is to respond to your needs, be attuned to your needs, and help you achieve what goals you have.’ Sometimes the staff mindset is, ‘My role is basic caretaking: to feed you and keep you safe.’ There’s another next level in care that needs to happen. We have a lot to do in this area.” – Guild leadership staff*

- *Evening and overnight support:* The majority of mental health crises occur during the evening and overnight shifts. Leadership staff noted that individuals are well-supported during the day due to the presence of an array of clinicians, but the limited number of staff available after hours contributes to the escalation of challenging behaviors. Additionally, interviewees commented that the lack of on-call clinicians and lack of established relationships with external clinical response teams means staff must rely on 9-1-1 emergency services, which often further escalates the behaviors and leads individuals to be evaluated in the ED.
- *Post-crisis intervention:* Interviewees discussed inconsistent and incomplete follow-up to mental health crises. After a mental health crisis, factors that contributed to the crisis should be addressed. Often, the individual’s plan is adjusted with altered staff ratios, medication changes, amended behavior strategies, and a new safety plan. Sometimes, a formal debrief process from CPI is used to review incidents and problem solve. However, few interventions occur for the staff or other residents, who may have been involved in the crisis or be feeling nervous after the crisis. Balancing the needs of the many residents and staff is undoubtedly challenging, but interviewees commented that follow-up to mental health crises must consider both the individuals and their environments, rather than just the individuals themselves. More comprehensive post-crisis interventions may help reduce the number of times that individuals continue to escalate their behaviors when they return from a crisis.

*“We need to look at what is causing crisis to happen. The same gaps exist before and after a behavioral disturbance.” – Guild leadership staff*

*“I know what should happen. What should happen is part of that discharge process is working with the external clinical team and our clinical team here and making any adjustments to their plan to better serve them here. That does happen a good portion of time, but sometimes people get discharged back to us really quickly and we have to scramble... So, it doesn’t happen all the time.” – Guild leadership staff*

*“In my view, we need a highly trained clinical person when an incident like this happens to be able to respond when somebody comes back. Not saying in person, but someone who can be on the phone with staff explaining what staff needs to do.” – Guild leadership staff*

#### *Massachusetts*

- *Police and EMT training on IDD:* Community resources like police and EMTs often have limited experience and training in working with individuals with IDD. This lack of training

contributes to harmful interactions between these responders and individuals at the Guild experiencing mental health crisis. Though some departments have improved their training in this field, others still lag behind, which contributes to unnecessary ED visits and imprisonment. Notably, on December 31, 2020, the Massachusetts legislature passed Bill S.2963, which requires the Committee on Police Training and Certification to develop training on interactions with persons with ASD and other IDD.<sup>42</sup>

*“Police aren’t well-trained to work with patients with IDD and mental health. They say things like, “She has autism, so she’s going to be aggressive.” – Guild leadership staff*

- *Intermediate level of care:* Nearly every member of the Guild leadership staff named the lack of an intermediate level of care as a significant gap in services. Guild students and residents very rarely meet criteria for inpatient psychiatric admission. Even when they do meet criteria, inpatient units for neurotypical children and adolescents almost always decline patients with IDD. Specialized inpatient units in neighboring states are also often full. Thus, students and residents find themselves in a grey zone: they are not able to be placed at an inpatient bed, but they are also too acute for the group home, which are the only two discharge options currently available for ED providers.

Two consequences of this grey zone are ED boarding and ED cycling. Students and residents often stay at the ED for up to a week awaiting placement, which is not beneficial to their care. The ED can be loud, unfamiliar, and overstimulating for many individuals with IDD. After prolonged ED boarding, students and residents are usually discharged back to the group home. Discharge to the group home while individuals are still in crisis contributes to what interviewees described as a “vicious cycle” of going back and forth between the group home and the ED. When individuals prematurely return to the group home, they often quickly escalate behaviors again to the point where Guild staff request evaluation and stabilization in the ED.

Because of the amount of ED boarding and ED cycling, leadership staff suggested the need for intermediate levels of care between the group homes and the ED, which is discussed further in the **Possible Programming** section.

*“When somebody is in crisis and needs a safe secure setting, we do not have that available within our milieu. We can do the med changes and we can do some of the things that need to happen, but we don’t have a secure place for all of that to happen. We do not have the physical resources you need when in this situation: a higher level of care. We do not have the availability within the current configuration to do that.” – Guild leadership staff*

*“An in-between level of care is needed between hospital level of care and residential care... Not long-term. Definitely something that people would come back from... It would be great if I had a place where I could say, ‘Go here for five days and take a little vacation. We’re going to beef up your supports during this time, and then you’re coming to come back to a great plan to transition you back into the program.’*

*We could use two weeks to look at this programming and figure out what's working and what's not working. What's the antecedent for the behavior? Is it medication related? And I think that's a gap. I don't think based on our current set-up that we have the means to do that within our current programming."* – Guild leadership staff

*"There isn't [a level of care]. That's the problem. They sit in the ER instead. There isn't a care option at this point. The ER also loves to discharge kids at 3AM when we have limited staff, which contributes to the back-and-forth pattern."* – Guild leadership staff

*"It's unproductive for a kid to stay in the ED. This just makes it worse... Most students return back quickly, but some will stay in the ED for 24 hours to a week waiting for a bed. The emergency room is not a place to get services. That's why we try to avoid sending students to the hospital. Our kids rarely meet level of care requiring inpatient and spend a long time waiting for beds."* – Guild leadership staff

### *New England*

- *Young adults:* Mental health services for young adults with IDD have been recognized as a significant gap, not only in Massachusetts, but in the New England region as a whole. In Massachusetts, DCF services begin to fall off at age 18 and end completely at age 22. Individuals are eligible for DDS at age 22, but many have a delayed transition due to the application process. This lag and transition in services often contributes to the escalation of challenging behaviors in young adults with IDD.

When young adults are in crisis, there are limited mental health settings where they can receive treatment. Nearly all of the specialized psychiatric units are for children and adolescents, meaning they do not accept individuals who are 18 years of age or older. In the past, young adults with IDD were admitted to general adult units. However, young adults often struggle on adult units where most patients are significantly older than them. Interviewees also expressed concern that young adults with IDD may be vulnerable and scared if placed on general adult units. They also commented that those units were unhelpful for the individuals because the groups, therapies, and approaches for neurotypical patients are often ineffective for individuals with IDD.

*"It's really bad in young adults, the 18 to 22-year-olds. It's a tough population because they don't fit on an adult unit, especially because of their IDD, but they also don't fit on an adolescent unit legally because of their age. We also see more crisis with this population because they are going through transition, which is difficult for this population. There's been historically a gap in this population... It's difficult to find the right place for them with a multidisciplinary approach. Inpatient units that are not specialized do not have the right behavioral approach; they don't have that ABA approach."* – Guild leadership staff

*"There are specialized hospital beds available for children and adolescents up to age 18 at Bradley Hospital in Rhode Island and Hampstead Hospital in New*

*Hampshire... Hampstead used to serve people until age 22, but they just recently changed that... So, there are resources from ages 13 to 18, but no inpatient services for people age 18 to 22. Also, acute and intensive residential services in locked settings, like JRI (Justice Resource Institute), a large provider that contracts with the state, all end at age of 19. Also, CBAT units like Wayside and Franciscan all end at age 18. So, from 19 to 22, the only option becomes inpatient adult units. None of those adult inpatient units that take 19 to 22 are equipped for clinical services with IDD.” – Guild leadership staff*

## 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*

*“Respite. I feel like this a lot for our kids. They’re in our program 24/7, every day of the year. They very rarely get time off. I get vacation days where I can take a week off. Our kids don’t get that. It would be amazing to say the first weekend of every month they get to go away. Kids get worked up and need a break, but I don’t have a way to give them that... As much as kids with autism like consistency and schedule and routine, there’s still a point where you need a break.” – Guild leadership staff*

*“[Respite] staves off and prevents crisis. You can’t underestimate the power of giving a caregiver a break or a reset switch. All of that can be valuable to head off externalizing behaviors such that a person can’t be in their usual living situation.” – External expert on IDD*

Three members of the Guild leadership staff discussed the need for respite when asked, “What do you feel is needed to better serve these individuals?” Two interviewees envisioned respite as a response to a mental health crisis. They saw respite as an opportunity to place individuals in a safe, therapeutic environment that could provide evaluation, counseling, behavior plan adjustments, and medication management. Importantly, this version of respite would still maintain structured programming, goals, and regular meetings for the individuals. Respite would also provide time and space for the group home staff to carefully consider and implement interventions that could prevent the crisis from occurring again. These interventions may include



altered programming, problem solving with staff, and debriefs with involved residents. They drew a connection between respite and being able to more effectively complete the **post-crisis intervention** discussed in a section above.

Critically, respite may be beneficial for both the residents and the staff. Working with individuals in mental health crisis can be extremely challenging: staff have previously been injured and have experienced traumatic events. Interviewees commented that time apart between residents and staff may prevent crises from continually occurring in a short period of time.

Another interviewee discussed planned respite, not in response to crisis, but as a strategy to prevent crisis. The interviewee proposed a staffed apartment with limited demands or expectations. The residents at respite would still have access to their preferred activities. However, the interviewee also noted that this program would have to be approached carefully, expressing concern that some individuals may become attached to respite and have difficulty leaving respite.

### 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. It is something that, if somebody were to want to do that level of care, it would be cheered and reimbursed well... 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. Many of them are boarding at home, which indicates they probably don’t need a hospitalization. If you can board at home, you probably don’t need to go to the hospital. And they’re there waiting for 30 days. I mean ridiculous... Ridiculous. That’s every day. Unlike the kids who don’t have autism spectrum disorder, there’s a constant flow of kids all year. They’re not as impacted by season. Generally speaking, the need for acute services goes down dramatically in the summer. But that’s not the case for kids on the spectrum. If one were to have a 12 to 16 bed CBAT, it would easily be full all the time with kids coming and going.*

*If the Guild were to come to the table tomorrow and say we’d like to talk to people very high up in Medicaid and DMH (Department of Mental Health) about potentially opening a CBAT, we would clear our calendars and set up a meeting and say, ‘Let’s talk. What do you want? What do you need? What’s your model?’ There’s so much desire to solve the problem.” – Katherine Ginnis, Senior Director of Child, Youth & Family Policy and Programs, MassHealth*

Two members of the Guild leadership staff discussed the need for CBAT when asked, “What do you feel is needed to better serve these individuals?” Katherine Ginnis, Senior Director of Child, Youth, and Family Policy and Programs at MassHealth, also expressed emphatic support for a CBAT for individuals with IDD. Although some CBATs admit patients with IDD, they are not specialized. The parent interviewee expressed disappointment with the CBATs that their child was admitted to, stating that the CBAT did not know how to work with individuals with IDD.

Ginnis similarly reported that, because existing CBATs do not have specialty in IDD, youth with IDD often do not benefit from their CBAT stays.

An external expert on IDD advised that a dedicated CBAT program would be a substantial, though worthwhile, investment. A provider team similar to the inpatient level, with psychiatrists, BCBAs, social workers, speech and language therapists, and occupational therapists, would be needed. Programming would ideally be based on ABA principles with consistent utilization of data to target behaviors. Due to the extensive programming needs, a higher staff ratio would also be needed. Ginnis also suggested co-locating a partial program within the CBAT that could be modeled after successful partial programs like Spring Harbor Hospital in Maine, Bradley Hospital in Rhode Island, and Children's Hospital Colorado. A partial program would contribute to establishing a robust continuum of care for individuals with IDD.

Ginnis believes that a CBAT dedicated for individuals with IDD has not previously been built because of the concern that beds would stay empty; CBAT beds are reimbursed on a per diem rate, which means, if beds are empty, then the CBAT would be financially unviable. However, Ginnis expressed confidence that the CBAT beds would be easily filled with patients. A previous report found that, although the incidence of mental health crises is highly seasonal for neurotypical children and adolescents, the incidence is consistent throughout the year for children and adolescents with IDD. Ginnis also addressed the concern that patients would get “stuck” and have difficulty being discharged. MassHealth has worked closely with agencies to ensure that patients do not get “stuck” and find placements. Additionally, Cambridge Health Alliance has plans to open a dedicated inpatient unit for this population, which could work symbiotically with the CBAT to provide step-up and step-down services for each other.

### *Long-Term Stabilization Unit*

*“It should be a locked unit, like a miniature Hogan... It’s a longer-term placement... Some people need Hogan for that level of care, where they stay 6 to 18 months. Some people need that level of stabilization.” – Guild leadership staff*

*“[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*

Three members of the Guild leadership staff and the parent interviewee discussed the need for a long-term stabilization unit when asked, “What do you feel is needed to better serve these individuals?” The interviewees commented that a long-term, locked unit would provide the time and security needed to make lasting, impactful changes. All four suggested modeling the program after the DDS Hogan Evaluation and Stabilization Unit.



### **Featured Model 6: DDS Hogan Evaluation and Stabilization Unit**

The DDS Hogan Evaluation and Stabilization Unit is located in Danvers, Massachusetts and serves adults with IDD who are experiencing treatment-resistant mental health crises. Similar to inpatient level of care, the unit is locked. The model is centered on its extended length of stay, which ranges from a few months to a few years. The median length of stay is one year. This time provides clinicians the opportunity to taper patients off unnecessary medications, reduce polypharmacy, and find the right medications. While adjusting medications, the team also works with the patient on the challenging behaviors that led them to Hogan through therapy and groups. Emphasis is placed on positively supporting each patient. Data is used to track the frequency of challenging behaviors throughout each individual's stay and determine when an individual is ready to return to the community.

The clinical team is large and multidisciplinary. A primary care physician and physician's assistant are on the unit to respond to crises and write stat orders. A psychiatrist and pharmacist manage medications, a behavioral psychologist provides counseling and tracks data, and a social worker serves as the liaison with a patient's family. Occupational therapists and speech and language therapists are frequently consulted. Additionally, a team of nurses and behavior staff support patients in the milieu.

The program serves about 20 patients at a time with each patient provided an individual room. Common spaces include a day room, vocational center, greenhouse, recreation room, swimming pool, and gym. There is active programming with groups throughout the day.

Interviewees discussed current Guild residents who were formerly at Hogan and made remarkable progress during their stay. A common theme was that the residents spent extended periods of time in the ED due to mental health crises; however, they stabilized at Hogan and now reside at the Guild's group homes with minimal challenges. Interviewees also noted that building a program like Hogan would be a significant investment that would require partnership with a local hospital that could medically respond to crises.

Another member of the Guild leadership staff expressed hesitation about the Hogan model. A core value of the Guild is improving the quality of life of individuals, but Hogan limits exposure to family and community and seems restrictive compared to the Guild's other services. Though the interviewee recognized that some individuals are safer in settings like Hogan, they would only feel comfortable with the Hogan model if there were clear criteria for entering and discharging from the program.

## **Summary of Key Findings**

This needs assessment used secondary sources, peer-reviewed literature, internal records, and key informant interviewees to determine how crisis care for individuals with IDD can be improved for students and residents at the Guild, as well as in Massachusetts and the New England region.

The most important findings of the different components of this needs assessment include:

**Key Finding 1: Diagnoses of IDD are increasing in frequency, but the availability of specialized mental health services for this population remains limited.**

Diagnoses of IDD, particularly ASD, are becoming increasingly common. About 1 in 54 children in the United States is diagnosed with ASD, and the number of individuals diagnosed with ASD

has increased 6 to 15% every year since 2002. Despite this growing prevalence, access to mental health services continues to remain extremely limited, even more than the general population due to the need for clinicians with experience and training with IDD.

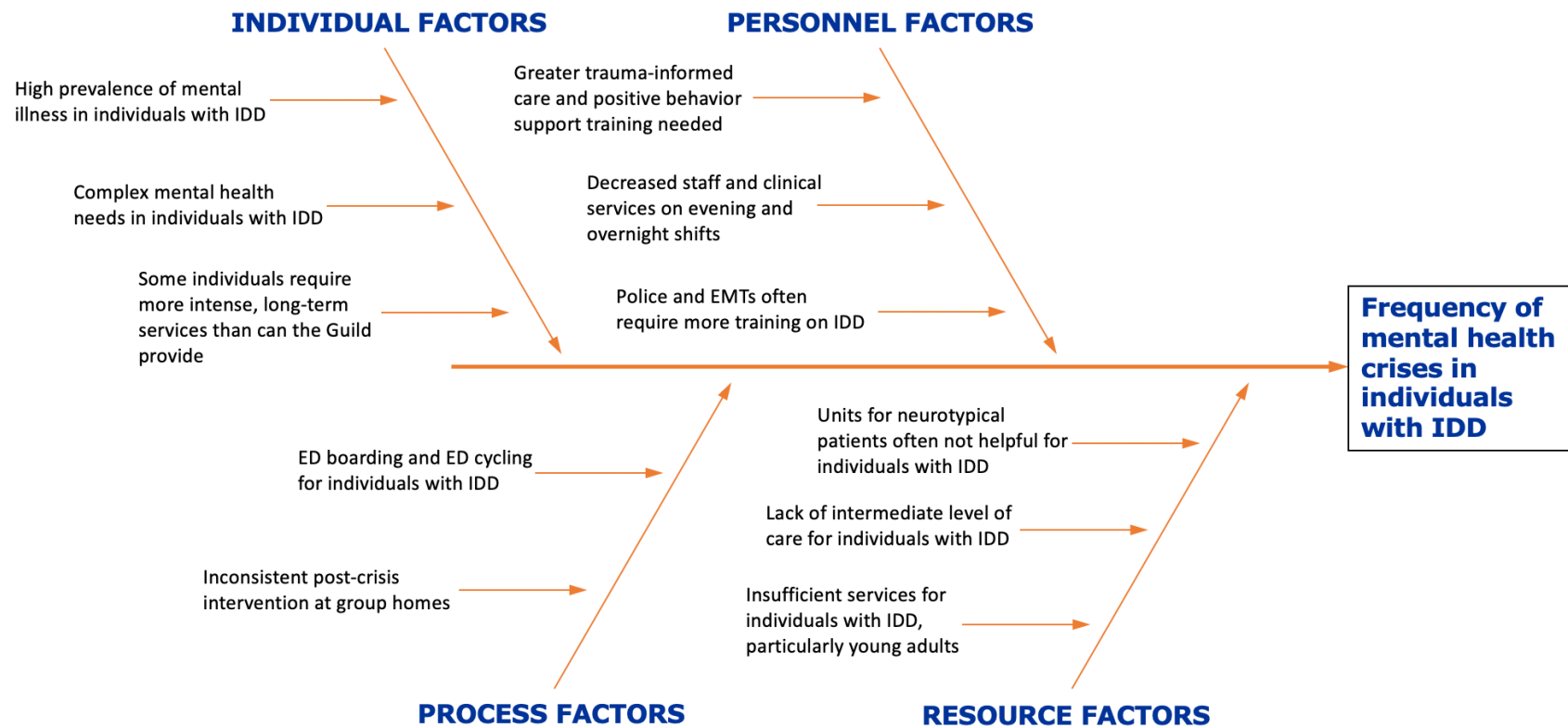
**Key Finding 2: ED boarding is a significant challenge for individuals with IDD.**

A direct consequence of the limited mental health resources for this population is ED boarding, the practice of awaiting mental health care for an extended period of time in the ED. This was highlighted as a pressing concern in both the secondary data sources and the key informant interviews. Individuals with IDD are more likely to require an ED visit for a mental health crisis than individuals without IDD. At the ED, individuals with IDD are more likely to board, board for longer durations, and be subjected to seclusion and restraints than individuals without IDD. Guild leadership staff also reported students and residents boarding at the ED for up to a week, which is detrimental to their care due to the unfamiliar, stimulating environment.

**Key Finding 3: A number of factors influence the frequency of mental health crises.**

There are many factors that contribute to the elevated frequency of mental health crises in individuals with IDD. The factors most relevant to the Guild are listed below (**Figure 3**):

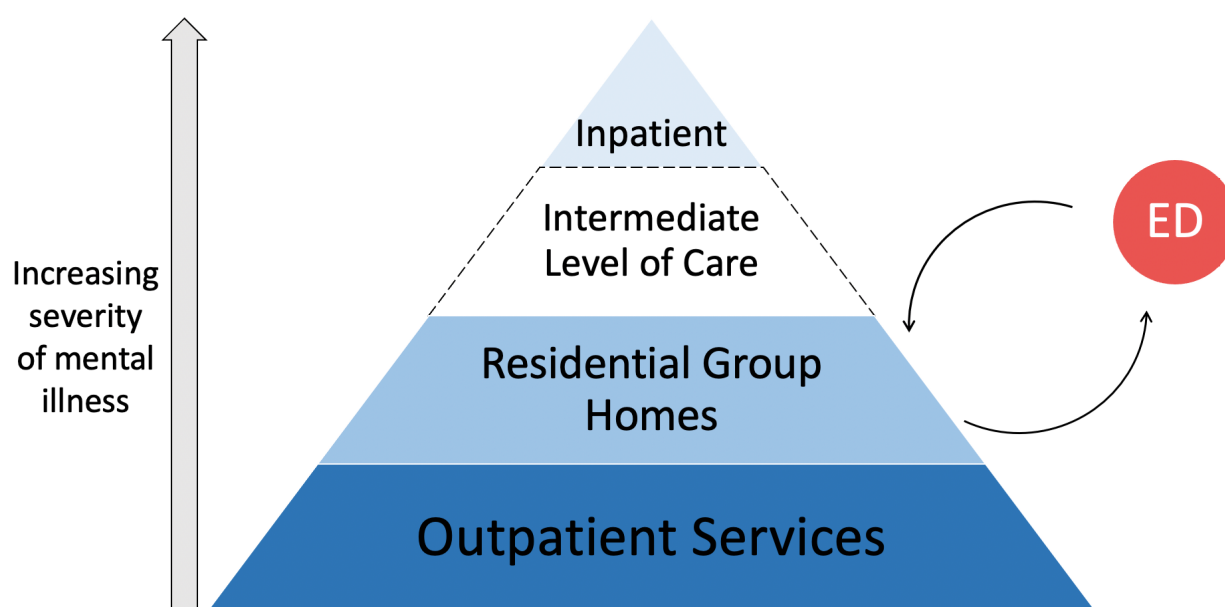
- *Individual factors*
  - There is a high prevalence of mental illness in individuals with IDD.
  - Co-occurring IDD and mental illness can have a complex presentation that is challenging to evaluate and treat.
  - Some individuals may require a more intense residential program with greater clinical resources and higher staffing than the Guild can provide.
- *Personnel factors*
  - More training on trauma-informed care and positive behavior support is needed.
  - Decreased staff and clinical services in the evening/overnight contributes to the majority of mental health crises occurring during these shifts.
  - Police and EMTs are often insufficiently trained on IDD.
- *Process factors*
  - Many individuals with IDD spend significant amounts of time boarding in the ED, as well as cycling between the ED and the group homes.
  - Dedicating time to adjust programming and debrief with the individual, involved students and residents, and staff may prevent future crises.
- *Resource factors*
  - There is a clear shortage of mental health services for individuals with IDD across all age groups, though this is especially lacking for young adults ages 18 to 22.
  - Individuals with IDD often do not benefit from general inpatient and CBAT units, which do not have clinical expertise or services for individuals with IDD.
  - An intermediate level of care between residential group homes and inpatient units is critical to addressing ED boarding and cycling (described further in **Key Finding 4**).



**Figure 3.** Cause-and-effect diagram of individual, personnel, process, and resource factors that influence the frequency of mental health crises in individuals with IDD.

**Key Finding 4: 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.**

The most common gap in mental health crisis care mentioned in the interviews was the lack of an intermediate level of care. When the Guild's students and residents experience mental health crisis, they rarely meet criteria for inpatient admission. However, they are often still too acute for the staff at the Guild's group homes. Consequently, students and residents find themselves in a grey zone where they are not an appropriate fit for any currently available care setting. This in turn leads to ED cycling, when students and residents go back and forth between the group homes and the ED in a short period of time. As discussed in the **Key Informant Interviews**, this level of care may be respite, CBAT, or a long-term stabilization unit. **Figure 4** illustrates the need for this intermediate level of care.



**Figure 4.** A continuum of mental health resources, such as outpatient services, group homes, inpatient units, and more, must be available to meet the needs of a population. The Guild provides group homes for individuals with IDD, but a proportion of these individuals experience mental health crises that require a higher level of care and are taken to the ED for evaluation. However, their crises often do not escalate to the severity of requiring inpatient admission, which leads them to be discharged back to the group home, for which they are too acute. This leads to ED cycling, when individuals shuttle back and forth between the ED and the group homes because they are not an appropriate fit for any currently available mental health setting. This cycling underscores the need for a level of care between an inpatient unit and the residential group homes.

**Key Finding 5: A significant number of youth with IDD require more intensive long-term settings than the Guild can provide.**

Between January 2017 and February 2021, 179 youth applications were turned down by the Guild. More than 60 of these applications were turned down due the intensity of the individuals' clinical and mental health conditions. More than 30 were turned down due their histories of bolting/elopement/running away. Ten more were turned down due their high staffing needs. Clearly, more intensive long-term settings are needed that can respond to these needs.

**Key Finding 6: Mental health services are especially limited for young adults with IDD.**

Young adults with IDD are often undergoing a great deal of transition. Many are transitioning from DCF to DDS and must move to new, unfamiliar settings because they no longer qualify as youth. Overall, there is an extremely limited number of services available for young adults between the ages of 18 and 22 if they experience mental health crises. They cannot be admitted to specialized child and adolescent units due to their age, and there are rarely beds available for them on adult units.

**Key Finding 7: There is growing body of research on effective interventions for individuals with IDD who experience mental health crises, and several models of care exist.**

The models discussed in the literature review varied significantly in their size, staffing, funding, services, and environments. They ranged from inpatient units to crisis stabilization centers. One of the most promising and well-published models is START, which provides community-based crisis intervention. A few common themes have emerged that may guide the Guild in creating its own programming for students, residents, and other individuals with IDD in mental health crisis.

- *Programming:* Nearly every program emphasizes individualized treatment plans that leverage multi-disciplinary teams, which includes psychiatry, psychology, ABA, speech and language therapy, and occupational therapy. Additionally, caregiver involvement during the program is critical as caregivers are educated and coached on best practices.
- *Environment:* Ideally, all patients have single rooms. The schedules and physical spaces of the programs are highly structured to accommodate the needs of the patient population. The low-stimulating environments may have muted lighting, subdued colors, and clear visual schedules and cues. The day is also scheduled with school, groups, and other activities to provide a regular routine for the patients. Furthermore, some programs feature picture exchange or other communication systems for minimally verbal patients, as well as sensory rooms that provide a place for patients to calm down if behaviors escalate.
- *Staff:* The programs all maintain high staff-to-patient ratios. The staff are extensively trained to work with this unique patient population. External experts believe that no single approach is wholly sufficient – a hybrid of approaches must be provided. Recommended training programs include Safety-Care Behavioral Safety Training, Registered Behavior Technician certification, TEACCH, trauma-informed care, and positive behavior support.
- *Funding:* Programs are highly dependent on insurance reimbursements to fund clinical care, though programs vary in the proportion of funding from public and commercial insurances. Besides insurance, some programs receive grant funding for activities. For example, the Crisis Response Center receives block grants since it provides a unique service that requires standing funding.<sup>43</sup> The Autism Inpatient Unit at the Hospital for Special Care was also awarded a \$500,000 grant by Connecticut's DDS to establish its services.<sup>30</sup>

### **Key Finding 8: Data related to mental health crises at the Guild should be tracked.**

To improve mental health crisis care for Guild students and residents, data related to the mental health crises should be aggregated and tracked. Currently, this data is not easily accessible. As the Guild transitions to an electronic record system, the Guild may prioritize making this data easily accessible to guide future improvement efforts. Suggested indicators for the Guild to monitor include:

- 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.

### **Next Steps**

In summary, this report has completed steps 1 through 4 of the six-step needs assessment process described in **Figure 1**. This project has defined its purpose and scope (step 1), gathered both primary and secondary data (step 2), analyzed the data (step 3), and identified factors that contribute to mental health crises in individuals with IDD (step 4). This report has also identified opportunities that the Guild may target to improve crisis care. However, this needs assessment conducted during the COVID-19 pandemic has a number of significant limitations. Critically, this assessment was unable to capture the perspective of the Guild's most important members: the students and residents themselves. Additionally, only one parent was interviewed. Research suggests that community participation is essential to implementing effective and sustainable public health interventions.<sup>44</sup> The next steps, selecting a program focus (step 5) and validating the program's need (step 6), should actively involve students, residents, family members, and staff in the planning process.

Ultimately, individuals with IDD currently do not receive the care that they deserve when they experience mental health crises. Although the Guild, Massachusetts, and the New England region have many strengths in supporting this population, more work must be done to fully meet their needs during crisis. The Guild may have an opportunity to both refine its internal services as well as establish a new program to meet the immense gap in acute services for individuals with IDD in the state and beyond.

## Appendix

### Appendix A. Acronyms and Abbreviations

ABA – Applied Behavior Analysis  
ASD – Autism Spectrum Disorder  
BCBA – Board Certified Behavior Analyst  
CDC – Centers for Disease Control and Prevention  
CMHC – Children’s Mental Health Campaign  
CPI – Crisis Prevention Institute  
DCF – Department of Children and Families  
DDS – Department of Developmental Services  
ED – Emergency Department  
EMT – Emergency Medical Technician  
ESP – Emergency Services Program  
IDD – Intellectual and Developmental Disability  
MCI – Mobile Crisis Intervention  
START – Systematic, Therapeutic, Assessment, Resource, and Treatment  
TEACCH – Treatment and Education of Autistic and Related Communication Handicapped Children

## Appendix B. List of Informants Interviewed

<b>Name</b>	<b>Organization</b>	<b>Position</b>
Mark Boilard	The Guild for Human Services	Director of Youth Residential Services
Robert Christian, MD, FAAP	University of North Carolina at Chapel Hill School of Medicine	Assistant Professor of Psychiatry and Pediatrics
Maureen Costello-Shea, MEd	The Guild for Human Services	Chief Program Officer
Fabiana Fickett, BCBA	The Guild for Human Services	Director of Behavior Services
Katherine Ginnis, MSW, MPH	Commonwealth of Massachusetts	Senior Director of Child, Youth & Family Policy and Programs, MassHealth
Mark Hauser, MD	The Guild for Human Services	Head Psychiatrist
Jennifer Magnuson, MA, BCBA	The Guild for Human Services	Chief Clinical Officer
Michelle McGonagle, LICSW	The Guild for Human Services	Director of Mental Health Services
Edwin Mikkelsen	Department of Developmental Services, Transition Unit	Head Psychiatrist
Parent (requested to be anonymous and not directly quoted in the report)	-	-
Matthew Siegel, MD	Maine Behavioral Healthcare	Director of Developmental Disorders Program
Jennifer Smith, RN, JD	The Guild for Human Services	Director of Health Services
Allison Traub, LMHC	The Guild for Human Services	Adult services behavior clinician



## Appendix C. Internal Informant Interview Guide

This interview is part of a needs assessment about the care for Guild students and residents when they experience mental health crises. For this interview, I am specifically interested when a crisis escalates to the point where staff no longer feel they can care for an individual by themselves and require external support.

1. For background information, could you please share your position in the Guild and how long you have been working at the Guild?

### Current strengths and weaknesses

2. What are the Guild's strengths in caring for individuals in mental health crisis?
3. What gaps do you feel exist in caring for individuals in mental health crisis?
  - a. What about for children and adolescents?
  - b. What about for young adults?
  - c. What about for older adults?

### Outcomes

4. What is the crisis response as it exists today?
  - a. If a resident has a behavioral or emotional crisis, what happens?
5. What is the extent of these gaps in crisis response in terms of frequency?
  - a. How often do these crises occur?
  - b. How many of the Guild students and residents utilize ED and crisis services?
6. What care options are available for individuals experiencing mental health crisis?
7. What happens when individuals return after a crisis?
  - a. What is different in their care?

### Solutions

8. What do you feel is needed to better serve these individuals?
  - a. What is needed to help stabilize these individuals?
  - b. What would trigger this?
  - c. What ages would need this the most?

### Further information

9. Is there anything else you would like to say that is relevant to this topic?
10. Who else do you recommend I speak to about this?

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