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## A Neurobehavioral Continuum of Care for Individuals with Intellectual and Developmental Disabilities with Severe Problem Behavior

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### Abstract

The Neurobehavioral Programs at Kennedy Krieger Institute constitute a comprehensive continuum of care designed to serve individuals with intellectual and developmental disabilities with co-occurring problem behavior. This continuum includes inpatient, intensive outpatient, outpatient, consultation, and follow-up services. The mission of these programs is to fully integrate patient care, research, training, and advocacy to achieve the best possible outcomes with patients, and to benefit the broader community of individuals with severe behavioral dysfunction. The primary treatment approach utilized across all programs is applied behavior analysis, however the inpatient unit also provides fully integrated interdisciplinary care. Factors driving the development and expansion of these programs are described, as are the processes and systems by which the mission objectives are achieved.

### Introduction

The Neurobehavioral Programs at Kennedy Krieger Institute include several levels of service that constitute a comprehensive continuum of care designed to serve individuals diagnosed with intellectual and developmental disabilities (IDD) who have co-occurring problem behavior. The Neurobehavioral Programs have evolved over time to meet the varied needs of the population served, and presently include consultation, outpatient, intensive outpatient, inpatient, and follow-up services. The mission of the Neurobehavioral Programs is to fully integrate patient care, research, education, and advocacy to achieve the best possible outcomes with the patients served, and to benefit the broader community of individuals diagnosed with IDD with severe behavioral dysfunction. Located in Baltimore, Maryland, Kennedy Krieger is an institution dedicated to improving the lives of children and young adults with pediatric developmental disabilities and disorders of the brain, spinal cord and

musculoskeletal system, through patient care, special education, research, and professional training.

### **The Population Served**

Individuals with IDD are at increased risk for problem behavior (Gurney et al., 2006). The range of problem behavior seen in this population include self-injurious behavior (SIB; e.g., head banging, head hitting, self-biting), aggression (e.g., hitting, kicking, biting others), destructive behavior (e.g., destroying property), pica (ingestion of inedible items), elopement or wandering (leaving from a supervised area without caregivers' awareness), and other dangerous topographies of problem behavior. The etiology, emergence, course, and presentation of these problems vary widely, and can include a combination of genetic, neurological, psychiatric, developmental, and learning histories. Individuals may have one type of problem behavior, or multiple types; and these problematic behaviors can be transient and relatively mild for some individuals, and chronic and severe for others. The patterning of these behaviors can vary greatly, occurring almost constantly in some and episodically in others. Problem behavior can co-occur with various types of emotion dysregulation characterized by irritability, reactivity, and dysthymia (Mazefsky et al., 2020). Problem behavior can interfere with educational instruction, cause injuries including permanent disfigurement and loss of function, and lead to emergency hospitalization (Vasa et al., 2020), excessive medication (Espadas et al., 2020), restraint/seclusion (Sturmey et al., 2005), or long-term residential placement. Many of these challenges, including the limited availability of comprehensive services have been widely reported in the media (see Herman et al., 2021; Jewett, 2017; Leigh, 2021).

## **Theory and Rationale Behind the Approach to Treatment**

### **Approach to Treatment**

The primary treatment approach utilized across all services that constitute the Neurobehavioral Programs is applied behavior analysis (ABA). Many patients also receive services from other disciplines for medication management, medical care, and other therapeutic services by other providers at Kennedy Krieger or elsewhere. Interdisciplinary care is most fully integrated on the inpatient Neurobehavioral Unit (NBU) where ABA is applied in concert with pharmacological interventions in the context of a comprehensive interdisciplinary program (discussed further below). ABA is an applied discipline that seeks to understand and change behavior based on established principles of operant learning derived from the laboratory science of the experimental analysis of behavior (Baer et al., 1968). For individuals with autism spectrum disorder (ASD), ABA has generally had two broad domains of application. Comprehensive ABA interventions have been used widely with children with autism in educational contexts, which target global functioning and skill development (Smith et al., 2000). In contrast, focused ABA interventions are designed to address a specific concern such as problem behavior including aggression, SIB, and other behaviors that impair functioning and pose risks to safety. The Neurobehavioral Programs utilize focused ABA to address specific behavioral concerns, though many patients are also enrolled in comprehensive ABA-based programs elsewhere.

Problem behavior among individuals with IDD likely stems from a combination of deficits related to their disability, other comorbidities, and experiences that evoke and reinforce these behaviors. Deficits in adaptive skills, social interaction, emotion regulation, communication, and problem solving can set the stage for self-stimulatory behavior, irritability, and frustration, which can lead to problem behavior. As these behaviors are disruptive and potentially harmful, caregivers often react to assist or console the individual. Caregiver responses can inadvertently reinforce problem behaviors, particularly with individuals who have limited communication and adaptive skills, which can perpetuate and strengthen these behaviors over time. Although the interaction between deficits associated with IDD and the historical events that lead to the establishment of problem behavior cannot be directly examined in real time for an individual patient who presents with problem behavior, there are behavioral assessment procedures that can identify the variables that presently maintain problem behavior.

Functional behavioral assessment refers to a variety of assessment techniques designed to identify events in the environment that occasion and reinforce problem behavior (i.e., the operant reinforcing function, hereafter “function”). All of the Neurobehavioral Programs rely heavily on functional behavioral assessment for all patients. The most rigorous method to identify the function of problem behavior (functional analysis; Iwata et al., 1982/1994) involves observing problem behavior under controlled analog conditions that simulate situations in the natural environment. This includes conditions designed to mimic social reinforcement contingencies such as educational contexts where instructional demands are provided, situations where preferred items must be put away, and situations where a caregiver’s attention is limited because they are occupied, and sensory reinforcement contingencies where the level of stimulation in the environment is low or high. This methodology yields objective data that make it possible to identify the events that evoke and maintain problem behavior and thus classify it based on its function. Studies show that problem behavior is maintained by social reinforcement contingencies in most cases (approximately 65–75%), and by sensory stimulation in a minority of cases (approximately 25% of cases with SIB; Hagopian, et al., 2013; Iwata et al., 1994; Kahng et al., 2002; Kurtz et al., 2003). The more common social reinforcement functions of problem behavior include access to caregiver attention, access to preferred items, and escape from instructional demands (Beavers et al., 2013; Schlichenmeyer et al., 2013). Some problem behaviors also occur independent of social reinforcement contingencies, and are described as automatically maintained, as they are thought to produce their own reinforcement. Research has identified subtypes of automatically maintained SIB (Hagopian et al., 2017) based on specific and quantifiable patterns of responding in the functional analysis. For some individuals these behaviors occur at much higher rates under conditions where there is little stimulation in the environment suggesting SIB has a self-stimulatory function, but for others SIB occurs regardless of the level of stimulation present.

The function of problem behavior is its most important dimension, as knowledge of the operant reinforcing function informs the design of behavioral interventions that precisely target the mechanisms that evoke and maintain these problem behaviors for each individual. This approach to behavioral treatment has been the dominant approach for the treatment of problem behavior in this population and has strong empirical support spanning over

four decades (see meta-analyses by Didden et al., 1997; and Heyvaert et al., 2012). It also has been noted that this function-based approach to treatment mirrors the principles underlying precision medicine as both seek to apply interventions that directly target the causal mechanisms that give rise to dysfunction (Hagopian et al., 2018; Falligant & Hagopian, 2020). In as much as the function of problem behavior varies widely within and across cases, so do behavioral interventions. For example, treatments for problem behavior maintained by caregiver attention are very different than treatments for problem behavior maintained by escape from instructional demands. Although the behavioral interventions are highly individualized based on the function of behavior, common elements of most interventions include (a) reinforcement to strengthen adaptive behavior and establish new skills, (b) antecedent interventions to decrease the probability that problem behavior will occur, (c) the use of discriminative stimuli and other signals to increase predictability and make expectations more clear, and (d) extinction (the withholding of reinforcement for problem behavior) to weaken problem behavior and thereby promote adaptive replacement behaviors.

### **Resources Necessary for ABA.**

Delivering applied behavior analytic services is a staff-intensive endeavor, as the approach requires direct observation of behavior under controlled conditions where patient behavior is precisely defined, recorded, and later analyzed. This requires trained observers to record occurrences of multiple behaviors in real time using precise computerized behavioral data collection and analysis systems (Bullock et al., 2017<sup>1</sup>). Assessment and therapy sessions require highly trained staff to establish structured contexts as defined in assessment and treatment protocols, deliver repeated learning trials, apply multicomponent behavioral interventions (often involving prompting, delivering discriminative stimuli, delivering reinforcement under multiple or concurrent schedules), all while maintaining safety of the patient and themselves. Paper and pencil data collection is also used outside of scheduled assessment and therapy sessions to collect behavioral data enabling evaluation of behavioral and pharmacological interventions across time. The design of data collection systems, assessment and treatment procedures, and interpretation and analysis of behavioral data requires specialized training and credentials. All staff in the Neurobehavioral Programs responsible for developing and overseeing behavioral assessment and treatment strategies (Senior Behavior Analysts) are licensed psychologists and/or Board-Certified Behavior Analysts.

Patients with problem behavior that has caused injuries or is impacted by medical and/or psychiatric variables also require medical staff resources, and close collaboration across disciplines. The inpatient Neurobehavioral Unit (NBU) is described further below. In this context, functional behavioral assessment findings not only guide the development of behavioral interventions, but also are a valuable source of information to other disciplines to aid in differential diagnosis of medical and psychiatric conditions. As the factors contributing to the clinical presentation are identified, targeted behavioral, medical, and

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<sup>1</sup>BDataPro was developed on the Inpatient NBU, and is available free of charge on the Neurobehavioral Unit website: <https://www.kennedykrieger.org/patient-care/centers-and-programs/neurobehavioral-unit-nbu/bdatapro-software>. Analytics indicate this software has been downloaded over 6,000 times in the past two years.

psychiatric interventions can then be applied (Hagopian & Caruso-Anderson, 2010; Wachtel & Hagopian, 2006). As is discussed further, this level of care requires a dedicated interdisciplinary team working closely in concert, as well as additional staffing resources to meet the needs of hospitalized patients.

## The Establishment and Growth of the Neurobehavioral Programs

The Neurobehavioral Programs evolved from what was a small inpatient specialty program focused on the study and treatment of SIB with individuals diagnosed with an IDD. The Department Director, Michael Cataldo and a faculty member, Brian Iwata (who would be the director of the program), sought initial funding from NIH (1R01HD16052-01; \$200,000) and from a foundation, the Pew Memorial Trust (to establish the National Center for the Study and Treatment of Self-Injurious Behavior; \$420,000). They conducted a 6-state survey of potential admissions showing that state agencies had patients to refer that could fill the small projected census many times over. The Program was named the Self-Injurious Behavior (SIB) Unit and was housed on the Kennedy Krieger's general hospital floor. For the next two to three years, the SIB Unit maintained a census of one or two patients, most of whom were young, small, and engaged predominantly in SIB, albeit often at high rates and/or producing significant risk of tissue damage and loss of function (e.g., blindness). This initiative included research capabilities, which resulted in several publications, including the seminal paper on functional analysis (Iwata et al., 1982/1994). At the time of the inception of the SIB Unit, it was known to the founders that the problems treated by this program exist in the non-hospital world, have their genesis there, and treatment must be generalized and maintained there. Thus, assessment and treatment of such problems would ideally be in the community, rather than a hospital. However, the opportunity to create the SIB Unit in a hospital had several distinct advantages, including: (a) multiple medical and allied disciplines could be brought to bear to address the comorbid medical and psychiatric problems simultaneously with behavioral interventions; and (b) the hospital reimbursement rates allowed for the necessary level of services to be provided. The SIB Unit was assigned dedicated space within the Institute to accommodate growth, and architecturally designed to meet the additional safety needs for this patient population. Overtime, it began to serve patients with problem behavior other than primarily SIB such as property destruction and aggression, and was renamed the Severe Behavior Unit to better describe the population served. Years later it was renamed the Neurobehavioral Unit (NBU) to underscore its unique interdisciplinary approach to treatment. The Outpatient Program was a natural extension of the Inpatient Unit, as discharged patients needed follow-up services to maintain gains achieved while in the hospital. Over time, that program expanded into a distinct program designed to provide follow-up services and outpatient assessment and treatment to patients who were not in need of hospitalization. Over the ensuing years, the Outpatient Program grew organically (based on increasing referrals) in small increments. The outpatient space was architecturally designed with the safety needs for this patient population in mind: therapy rooms were padded to help protect patients from injury, waiting areas were separate from areas where medically fragile patients were located, and more trained staff were hired as outpatient census increased.

A pivotal point in the evolution of the Neurobehavioral Programs occurred through interactions with leadership in the Mental Hygiene Administration (now the Behavioral Health Administration) of the Maryland Department of Health (who worked collaboratively with Maryland Medicaid Administration). Leadership in that agency charged the Neurobehavioral Program leadership to work toward serving more Maryland residents for less cost per person. This resulted in a series of initiatives to develop models to decrease the number of inpatient admissions by expanding the Outpatient Program in size and increasing its capacity to serve individuals with more severe problem behavior. This eventually led to the development of the Intensive Outpatient Program (IOP) as an alternative to inpatient hospitalization (for a select group of patients that had severe problems but were thought to not require regular medical oversight or intensive pharmacological interventions). The IOP was designed to deliver the equivalent of a few months of outpatient treatment over a period of a few weeks (each of these programs are described further below). The expansion of these programs coupled with advances in behavioral treatment procedures enabled the outpatient programs to treat patients, and more severe problems – which also reduced the need for inpatient admission of Maryland residents. The cost per patient for Maryland residents was reduced as more were treated through the IOP and outpatient programs. As outpatient services grew, the Inpatient NBU concurrently sought to establish relationships with other states and payers – and identified itself as a program specializing in serving patients with treatment-resistant problems who had exhausted all local outpatient and inpatient services in their state. The inpatient census gradually increased to 16, and the referral base for the Inpatient NBU shifted from local, to regional, to national.

## The Neurobehavioral Programs Continuum of Care

Each referral to the Neurobehavioral Programs is carefully evaluated by behavioral and nursing staff (with additional consultation by medical and social work staff as needed) to determine the appropriate level of care within the continuum of services. When none of the programs are appropriate to meet the patient's needs, other providers within Kennedy Krieger, or other programs in the patient's community are identified and referrals made. See Figure 1 for a summary of all programs within the continuum of care.

Patients are triaged to the Outpatient Program if the family is within driving distance to one of the two sites (in Baltimore and Columbia, Maryland) and the patient meets the following criteria: (a) the patient has IDD and problem behavior that is interfering with functioning at home and/or school and lower levels of outpatient services have been unsuccessful, (b) the patient can be safely transported on a routine basis, and (c) the family can actively participate in treatment sessions for a minimum of two hours, two times per week. These patients typically receive behavioral services over a period of four to six months, during which time they can remain in school and live at home.

The Intensive Outpatient Program (IOP) is a more rapid and concentrated outpatient service model where patients receive up to 25 hours of service per week, typically for three consecutive weeks. Families accessing this service are either from the Baltimore/Washington area or they temporarily reside locally (e.g., at a hotel or a charity-supported accommodation) while completing the program. IOP is indicated when the patient meets

the above criteria for outpatient service, and (a) the problem behavior is quite severe and requires rapid and intensive treatment that would not be safe or feasible if delivered through regular outpatient care spanning a period of several months, (b) the patient can be managed safely in local housing, and (c) inpatient admission is not yet indicated. In some cases, Outpatient or Intensive Outpatient services may be provided via a telehealth model, wherein the parent is trained to conduct behavioral assessment and treatment sessions from home, and data are collected and reviewed by the clinical team stationed in the hospital setting.

The Inpatient NBU is the most intensive level of service and reserved for patients (a) with more severe and treatment resistant problems, (b) who have accessed all services available to them locally, been hospitalized in the past, yet remain at risk for injury or out of home placement, (c) for whom inpatient treatment is necessary to maintain safety and achieve the goals of treatment, and (d) their caregivers agree to actively participate in the admission and undergo intensive training to carry out recommended treatment protocols. On the Inpatient NBU, patients receive comprehensive interdisciplinary care, wherein both problem behavior and comorbid psychiatric conditions are targeted with integrated behavioral and psychiatric/medical intervention during a four to six-month hospital admission. After patients complete treatment in the inpatient or outpatient programs, they are referred to the Follow-up Clinic for behavioral follow up care, and medication management by an outpatient psychiatrist (patients residing out of state are referred to local providers). In addition to the on-site outpatient clinics and the inpatient unit, the Neurobehavioral Programs continuum of care includes Consultation services provided to individuals, hospitals, and programs across the country and around the world.

### **Inpatient NBU**

All programs across the continuum of care collaborate with other disciplines, however the Inpatient NBU is designed to provide interdisciplinary treatment. The Inpatient NBU has staff across multiple disciplines who are dedicated as core team members. Each patient is cared for by professionals specializing in the fields of behavioral psychology, psychiatry, pediatrics, neurology, nursing, social work, speech and language pathology, and education. As noted, a unique feature of the Inpatient NBU is the integration of behavioral and pharmacological interventions. This “Neurobehavioral Model of Care” recognizes that severe problem behavior often has multiple determinants, including those that are related to operant reinforcement contingencies, skills deficits, as well as medical, neurologic, and psychiatric co-morbidities. Functional behavioral assessment can precisely identify the events in the environment that occasion and maintain the problem behaviors of concern, and also inform medical and psychiatric diagnosis (see Wachtel & Hagopian, 2006; and Hagopian & Caruso-Anderson, 2010 for case examples and descriptions of this approach). Findings from these various assessments are then used to guide application of targeted and individualized behavioral, medical, and pharmacological interventions.

The following is a brief description of the responsibilities of each member of the inpatient interdisciplinary team. The Senior Behavior Analyst (SBA) is a licensed and credentialed psychologist and/or Board-Certified Behavior Analyst (BCBA), who directs behavioral assessments and treatment services. All SBAs hold faculty positions in the Department

of Psychiatry and Behavioral Sciences at the Johns Hopkins University School of Medicine (JHUSOM). Each patient has an assigned team of behavior therapists who work under the direction of the SBA to conduct behavioral assessment and treatment sessions; this includes a Clinical Specialist (who is assigned only one patient), and two Behavior Data Specialists (who work with two patients across staggered session times). Educational Coordinators devise and oversee the delivery of educational services, and interface with the patient's home school. Activity Coordinators arrange and lead recreational activities on the unit and off the unit to allow patients opportunities for leisure and supervised participation in group activities. Clinical Assistants are direct care staff, who attend to the needs of the patient outside of therapy sessions, carry out behavioral protocols, and collect behavioral data on the living unit. Unit Supervisors and Unit Coordinators train and supervise Clinical Assistants, and maintain the general safety and staffing of the unit across day, evening, and night shifts seven days per week.

The medical team is comprised of several personnel. The Child Psychiatrists are responsible for the patient's psychiatric care, and has specialized expertise in working with individuals with IDD. All are Board-Certified, credentialed medical staff, and hold faculty positions in the Department of Psychiatry at JHUSOM. The Child Psychiatrist works closely with the SBA to review behavioral data and coordinate behavioral and psychiatric interventions to ensure these interventions are applied in concert. The Pediatrician oversees medical care, works closely with the Pediatric Nurse Practitioner to address any medical issues, and seeks specialty consultations at Kennedy Krieger or Johns Hopkins Hospital as needed. Nurses staff the Inpatient NBU across all three shifts and work closely with the medical team to provide patient care. Nurses and Nurse Practitioners work closely with behavioral staff to ensure general unit safety as well as to ensure that patients are protected from their own SIB. The Social Workers' locate the resources and supports necessary for each patient's successful return to their home and community, and provide community advocacy support and care coordination to help the patient's family adapt to the challenges of meeting the special needs of their child. Speech and Language Pathologists conduct assessments, provide consultations, and treatment services in speech, oral motor skills, feeding, swallowing, language understanding, language expression, voice, and fluency. Each patient is evaluated to assess speech and language abilities and receives weekly, individual or group speech and language treatment sessions based on assessment findings. Speech pathologists also work closely with the behavioral treatment team on developing functional communication skills.

The Inpatient NBU and Outpatient Program spaces are physically designed to ensure safety of patients and to allow for intensive therapy. Session rooms have safety features such as padded walls and floors, and plexiglass over protected light fixtures and observation windows to minimize risks for patients with severe head-banging or other dangerous behaviors. All session rooms are connected to observation rooms where clinical staff observe sessions through a one-way mirror and collect data on laptop computers, video record sessions when needed, and enable caregivers to observe treatment sessions. The inpatient unit also has common areas and activity areas for therapy sessions when appropriate, or for educational and recreational activities for patients.



## **Common Elements of Clinical Services across all the Neurobehavioral Programs**

### **Caregiver Involvement**

Across all Neurobehavioral Programs, the parent/caregiver is considered an integral member of the treatment team and consent to all procedures during the first day of service. Caregiver involvement and active participation during their child's services is required and discussed prior to admission. Caregivers are interviewed to identify the behaviors of concern, their goals and preferences for treatment; and to obtain information about their child's skills, skills deficits, and potential reinforcers and preferred routines. For patients receiving outpatient services, caregivers attend each outpatient session in its entirety. Caregiver-child interactions are directly observed to provide the therapy team with important information on interaction patterns. Caregivers participate in baseline generalization sessions, naturalistic observations and the caregiver may even serve as the therapist during functional behavioral assessments. When not directly participating in sessions, caregivers are strongly encouraged to observe assessment sessions and provide their input to the behavior team regarding their child's behaviors. Caregivers of patients admitted to the Inpatient NBU attend regularly scheduled meetings with the Interdisciplinary team and are a key source of information during the assessment process. They receive frequent updates via phone from members of the interdisciplinary clinical team. Caregivers are educated on the causes of problem behavior, and trained on general behavioral procedures including prompting, reinforcement, and the benefits of structured daily schedules. They are informed about assessment findings and treatment options, and once an individualized treatment is developed and demonstrated to be efficacious, caregivers are trained in all the components of the recommended intervention. Caregiver training is conducted using behavior skills training (BST), which involves written and oral instructions and a rationale for the treatment, followed by observations of their child's therapist modeling the treatment, rehearsal via role playing, and faded practice with the child where the caregiver applies additional treatment components as easier ones are mastered. Data are collected on caregiver implementation of each component to guide feedback and ensure new skills are not added until prior ones are mastered. Once trained to mastery in implementation of the entire behavior plan (90% or greater correct implementation), the caregiver along with the behavior team practice the implementation of the behavior plan in the generalization settings identified by the caregiver as challenging prior to the admission (e.g., in a supermarket, toy store, waiting room, etc.).

### **Communication and Collaboration with Other Social Entities**

The short- and long-term success of services provided in the Neurobehavioral Programs relies on parents and caregivers, school staff and other community providers continuing to implement the interventions developed during Inpatient or Outpatient Services. Contact and collaboration with the patient's existing community providers is initiated prior to and during services. Without proper supports, families may have difficulty maintaining the patient's behavioral health once the child is discharged from our program. As part of the application process, caregivers complete a packet of information that includes all current and past supports. Supports can include anyone from family members to state agencies that are

involved in the care of the patient. The availability and funding of specialized professional and support services varies widely depending on location. The patient's Social Worker makes it a priority to find and identify appropriate community providers for the patient.

For school-age patients, developing and maintaining a relationship with school providers is not only integral to developing the behavior plan, but also necessary to help insert the plan into the child's Individualized Education Plan prior to discharge. The patient's school is contacted at admission, and information is gathered on problem behaviors that are of concern, the frequency and context in which each behavior occurred at school, and the supports available to the patient at school. Any existing behavior plans developed by the school and any data school personnel collected on the efficacy of the plan are also reviewed, along with information on how problem behavior may have obstructed learning new skills or impacted the child's current IEP goals. School policies and capacity to apply behavioral interventions are reviewed. Following the initial school contact meeting, meetings continue to occur (at a minimum) approximately every four weeks. Once the patient is closer to discharge, meetings between the patient's interdisciplinary team members and school staff may become more frequent to ensure all school supports are in place and that the school personnel feel they have a good understanding and training in the behavior plan found to be successful in reducing problem behavior. Typically, school personnel attending these meetings include the patient's teacher, behavior analyst/behavior resource personnel, speech pathologist, and social worker/case manager.

Despite attempts to coordinate services with community providers, patients with the most intensive needs are at risk for being denied services by many programs. Patients who have been successful in treatment are sometimes denied admission into programs because of a history of behavioral crisis and the possibility that crisis management procedures may be needed from time to time. Behavioral procedures and protective equipment demonstrated to be safe, efficacious, and medically necessary – and deemed necessary by parents are sometimes not allowed in certain jurisdictions, centers, or classrooms based on either philosophical beliefs or policies that fail to recognize the needs of those with more severe problem behavior. Consequently, forming partnerships with specialty schools and community-based residential programs that are willing and able to serve this population have proven critical to ensuring those with the more intensive needs can be served in the community.

## **Outcome Data**

### **Outpatient Program**

Outcomes for a sample of 724 patients served over a 23-year period (1994–2017) in the Outpatient Program are briefly summarized here. As noted, the Outpatient Program represents a traditional outpatient clinic-based service model. Most of the patients who are referred to the Neurobehavioral Programs are served in this program. Patients are typically seen two hours per day, two days per week, for a period of four months. Function-based behavioral interventions were found to be successful in reducing the targeted problem behavior by 80% or greater relative to pre-treatment baseline in 86% of patients; and

caregivers were successfully trained to implement treatment with 90% accuracy or greater in 80% of cases.

### **Intensive Outpatient Program**

Outcomes for a sample of 157 cases served over a 22-year period (1994–2016) by the IOP are briefly summarized here. As noted above, this service represents a level of care between inpatient and outpatient as patients are seen for up to 25 hours per week for three weeks. Function-based behavioral interventions were shown to be successful in reducing the targeted problem behavior by 80% or greater relative to pre-treatment baseline in 86% of cases; caregivers were successfully trained to implement treatment with 90% accuracy or greater in 88% of cases; and treatment gains were successfully generalized following treatment in 62.4% of cases. The rapid treatment effects obtained over a period of three weeks indicates this is an efficient model for treatment for many individuals with severe problem behavior.

### **Inpatient NBU**

Program evaluation data spanning two decades (1999–2019) for patients admitted to the Inpatient NBU were are briefly summarized here. As noted, inpatient admission is reserved for patients with the most severe and treatment resistant problem behavior, and is only initiated after outpatient treatment has been tried, or inpatient admission elsewhere has been tried and failed. Results indicate that approximately 88% of patients achieved at least an 80% reduction in their primary target behaviors relative to pre-treatment baseline. Of those patients that do not meet this goal, the vast majority demonstrate substantial reductions in the frequency and intensity of their problem behaviors. Although maintenance data (collected following discharge) are limited because most patients admitted to the NBU do not reside locally, 86% of caregivers returning patient data report they have maintained clinical gains up to 1-year after discharge. Readmission to the Inpatient NBU occurs in about 5% of cases admitted; many times parents report a stressor in the home interrupted the child's treatment, which contributed to an increase in problem behavior (e.g., death of a primary caregiver, divorce, moving to a new school district, etc.). Caregivers rated having "very good" or "excellent" satisfaction with the care their child received on the inpatient unit, and 96% of patients had at least one primary caregiver trained to 90% or better accuracy in their individualized treatment plan.

### **The Institutional Context**

The mission of the Neurobehavioral Programs is a direct extension of the mission of the institutions in which the Neurobehavioral Programs reside: Kennedy Krieger Institute and Johns Hopkins University School of Medicine (JHUSOM). Although distinct entities with independent governing boards, Kennedy Krieger and JHUSOM are academically affiliated and work in close collaboration at many levels. The vision of Johns Hopkins was to create a research university and a research hospital where the practice of medicine, medical education, and research would be integrated - and it was the first of its kind in the US. With legislation establishing the Association for University Centers on Disabilities (AUCD) nearly a century later, President John F. Kennedy's administration extended the

Hopkins tripartite mission to the field of developmental disabilities. The purpose of the AUCD was to promote research, training, and clinical services for people with IDD. This was to be achieved by the establishment of clinical centers, research centers, and training programs that were affiliated with universities. The clinical centers, now known as University Centers of Excellence in Developmental Disabilities (UCEDD), were designed to provide specialty clinical services to those with IDD. Kennedy Krieger was the first UCEDD in the nation; there are now 67 UCEDDs in the US. The training programs, currently known as Leadership Education in Neurodevelopmental and Related Disabilities (LEND), were designed to provide specialized professional-level training to prepare individuals from multiple disciplines for leadership positions serving those with IDD. Currently, there are 52 LEND Programs in the US, one of which is at Kennedy Krieger. The research centers, known as Intellectual and Developmental Disabilities Research Centers (IDDRCs), were designed to promote biomedical and behavioral research to better understand, prevent, and treat disabilities and the problems associated with these conditions. Currently, there are 14 IDDRCs in the US, one is at Kennedy Krieger. The mission of the Neurobehavioral Programs to integrate patient care, research, education, and advocacy is deeply rooted in the missions of these institutions.

### **Achieving the Neurobehavioral Programs Mission Objectives**

Extending the mission of Kennedy Krieger to the challenge of severe problem behavior for those with IDD, the Neurobehavioral Programs have evolved into a *learning health system*, with policies and resources embedded within its structure to support the integration of clinical service and research. Providing clinically excellent care is the primary objective of the Program's mission. To achieve this goal, leadership and clinical faculty maintain contact with the research literature and continuously modify procedures as new ones are developed and established. Robust program evaluation is driven by an obligation to learn from current and past clients and patients and use that knowledge to inform continuous improvement efforts. This is achieved by archiving, curating, and analyzing clinical data obtained as a by-product of service provision. The analysis of outcomes of clinical procedures across multiple cases makes it possible to perform quantitative analyses to examine the efficacy of clinical procedures, identify the optimal indications for their use, and identify their limitations to inform improvements and guide the development of new interventions. In addition, the analysis of clinical data can inform and inspire clinically relevant research questions, particularly when findings identify gaps in knowledge or reveal that established procedures do not produce desired outcomes. When findings are judged to advance knowledge and practice beyond the Neurobehavioral Programs, they are disseminated through presentations and publications in professional journals (with approval and oversight by Kennedy Krieger's Office of Human Research Administration and JHUSOM's Institutional Review Board).

### **The Provision of Clinical Services**

Expansion of the Neurobehavioral Programs in size and scope over the past three decades has been largely driven by patients' needs, and shaped by program leadership and other stakeholders. The continuum of care expanded beyond the inpatient model in 1991, to include outpatient care - and with that, the types of problems addressed and clinical

populations served broadened. The Neurobehavioral Programs now serve infants as young as 10 months, children, adolescents, and adults across the various programs within the continuum of care. Most patients have IDD (most are diagnosed with autism spectrum disorder), including disabilities that are idiopathic, genetic in origin, and some are diagnosed with acquired brain injuries. The broad continuum of services enables clinicians to match the type of clinical service to the unique and complex behavioral, medical, psychiatric and social needs of each individual. Collectively, the Neurobehavioral Programs have served over 4,000 individuals from 44 states in the US, as well as internationally (see Figure 2).

### Advancing Clinical Research

Evaluation of outcomes obtained within and across patients provides a feedback loop that identifies limitations of existing procedures and promotes efforts to improve them. When findings are shared and disseminated, this can further advance assessment, treatment, and knowledge on the nature of these clinical problems. Faculty of the Neurobehavioral Programs have been involved in the development and refinement of behavioral assessment and treatment procedures, some of which come to represent the standard of care in applied behavior analysis. This includes functional analysis of behavior (Iwata et al., 1982/1994), preference assessment procedures (Fisher et al., 1992), commonly used behavioral interventions (functional communication training and noncontingent reinforcement; Phillips et al., 2017; Rooker et al., 2013), and the extension of these interventions to young children (Kurtz et al., 2003) and individuals with genetic syndromes (Kurtz et al., 2008). In addition, questions raised in the course of providing services to individuals who have severe and treatment resistant problems has inspired formal research efforts to improve existing procedures and advance our understanding of these clinical problems. Findings also have led to advances in knowledge about self-injurious behavior including the identification of predictive behavioral markers (Hagopian et al., 2018). Faculty have also described a clinical model for the integration of behavioral and pharmacological interventions (Hagopian & Caruso-Anderson, 2010; Wachtel & Hagopian, 2006), and disseminated information on problem behavior and best practices related to early intervention, prevention, and treatment of problem behavior to medical professionals (Anderson et al., 2012; Kurtz et al., 2020; McGuire et al., 2016).

Program evaluation data have also been used to provide an empirical basis for numerous grant applications that have resulted in research projects funded by the National Institutes of Health (NIH), mostly through the Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD). To date, 13 NIH-funded grants have been awarded to faculty clinician-researchers within the Neurobehavioral Programs, totaling over \$13 M. Grants have supported translational research on problem behavior, clinical research on problem behavior and its emergence, research identifying subtypes of self-injurious behavior, and a randomized controlled trial for treatment-resistant self-injury to name a few. Faculty of the Neurobehavioral Programs have published over 300 articles in over 50 different peer-reviewed journals, including behavioral, medical, and interdisciplinary journals. Many of these articles have been highly impactful, and have contributed much to advancing knowledge of these problems, and promoting best practices for the assessment and treatment of severe problem behavior.

## Advancing Care through Professional Training

All of the Neurobehavioral Programs provide formal training to students in psychology and applied behavior analysis at all educational levels. To date, over 80 postdoctoral fellows and 150 pre-doctoral interns (enrolled in an American Psychological Association-Approved Internship Program) have trained in these programs. The Neurobehavioral Programs also have served as a placement site for more than 100 graduates of the Master's Program in Applied Behavior Analysis at the University of Maryland, Baltimore County. Former trainees and staff currently reside and practice in 43 states (see Figure 3) and in several countries. Some have established training and clinical programs at the university/college level, some hold leadership positions in service organizations, and most current faculty of the Neurobehavioral Programs are former trainees. The Inpatient NBU also provides formal training programs for professionals in neurology, psychiatry, nursing, speech and language, and social work under the supervision of faculty and staff from those disciplines. The Neurobehavioral Programs regularly host professionals from other facilities, from around the US and internationally, to share information about our service models and approach to treatment.

## Advancing Care through Advocacy

As providers of clinical services, researchers, and educators, faculty and staff offer an informed voice to advance the quality of care for individuals suffering from a severe behavior disorder, and encourage trainees to be involved in advocacy efforts. The Neurobehavioral Programs advocate on behalf of individual patients to help them access clinical, educational, and legal services; and the faculty and staff consult with agencies in Maryland and other states on best practices and regulations. They have assisted with training of First Responders, and contributed to efforts of professional and advocacy organizations, including the Behavior Analysis Certification Board, the Association for Behavior Analysis International, the Association for Professional Behavior Analysts, the National Association for Dual Diagnosis, and Autism Speaks. Faculty also have collaborated with insurance companies and public payers to promote and develop best practice standards.

## Lessons Learned

### Start Small

Most attempts at trying to replicate our program mistakenly start with a design that attempts to match the size and impact of our program in its current form. In contrast, we started with one bed in the early 1980's and significant time between admissions. To be successful with the most difficult cases, using a quasi-non-medical approach in a hospital, and implementing novel reimbursement criteria and rationales means that literally thousands of issues need to be identified, negotiated and resolved. To do so all at once generally does not work. Building toward a desired size and outcome works best if done a little bit at a time with progress coming with each successive resolution. The development of the program should be based on more than a grand vision, but on meeting a need in the community, bringing together the right expertise to meet that need, and sizing the program to meet the current need - with options for expansion should the needs increase or change. Behavioral treatment procedures have advanced to the point where most individuals can be treated in the home or school,

and in an outpatient clinic. The majority of expansion of the Neurobehavioral Programs in the past 15 years has been in the outpatient realm; and most patients can be treated in those settings particularly as the capacity to treat more severe problems with outpatient models increases. Although the need for inpatient admission has diminished for most patients who can access our Outpatient and Intensive Outpatient programs, it remains a necessary part of the continuum; and is a necessary resource for those who do not reside in areas where there is sufficient specialized expertise and resources available.

### **It's a Business Too**

That the program described here was a financial homerun continues to be as important as the fact that it is also world renowned clinically, has produced a high number of impactful scientific and scholarly publications, and arguably trained more professionals in this area than any other program of its kind in the world. The Neurobehavioral Programs are part of a non-profit institution: the goal is not to make profits, but to meet the mission objectives while remaining financially solvent. The program has been able to expand, change in response to changes in public and private funding mechanisms, and invest in new initiatives because it has been managed in a fiscally responsible manner. Important to note is that: (a) before the SIB Unit was initiated, a six state market analysis was conducted that defined the potential market size, price point, and cost of acquisition, (b) startup funding was obtained from external sources meaning that return on investment was easier to achieve, and (c) the use of data and strict internal controls ensured that no fiscal year resulted in a loss; and with efficiencies and economies of scale operating, margins grew. Growth in terms of size and type of services was based on the needs of stakeholders (patients, payers), and occurred incrementally. The often-touted adage, "Build it and they will come", is a risk-laden approach that one does not need to take.

### **Integration of Research and Treatment**

Research is a methodology that results in new knowledge. When research methods are used to evaluate outcomes achieved by clinical programs, as we did, the result was new knowledge – including information about the limitations of our clinical procedures and understanding of the problems we treat. The Neurobehavioral Programs learning health system has been central to the evolution of the program, has promoted the development of more efficacious clinical procedures, and has provided a foundation for inspiring clinically relevant research driven by our clinical experiences. Because of our integrative model of research imbedded in practice, we have been able to review and refine our clinical procedures thus improving outcomes with our patients, and disseminating that knowledge to advance care for others. We now can successfully treat a case in three weeks using an Intensive Outpatient model that two decades ago would have required an inpatient admission. This has resulted in fewer hospitalizations for those who can access our continuum, more individuals receiving treatment, and more efficient use of health care dollars. The integration of these activities has also provided faculty with data to inform efforts to obtain federal and foundation grant funding – and thus provide additional resources and time to study these clinical problems.

## Data, Data, Data

In real estate, the three most important factors are: Location, Location, and Location. In the endeavor described here, we would argue that the three most important factors are: Data, Data, and Data. In terms of decision processes, quantification of key variables and indices were used as the basis for almost all decisions be they clinical, financial, expansion, and the like. Group communication and processes are important, as is consensus building, but while everyone is entitled to their unique and specialized opinions, they are not entitled to their own facts. By basing decisions on objective metrics, actions can be quickly monitored and rapid changes instituted based on data.

## Conclusions and Future Directions

The Neurobehavioral Programs evolved over a span of four decades. Like any other entity, this required adapting to change. The mission to provide clinically excellent services, advance knowledge and practice, and promote access to services through training and advocacy has guided us to adapt to many changes, and has broadened our impact. Since the inception of the program, thousands of patients have been served from across the nation, standard of care procedures have been developed, refined, and disseminated, and knowledge of severe problem behavior has been advanced. Hundreds of professionals have been trained, and we have been privileged to partner with many families and organizations in advocacy efforts. The success of the Neurobehavioral Programs can be largely attributed to a combination of factors that linked it to the mission and the culture of the Kennedy Krieger Institute. The Institute defined rigorous standards for patient care, research, and staff management; laid out broad objectives, and provided support and guidance to program leaders at every turn since the inception of the program. Institute leadership also allowed the Neurobehavioral Program's leadership the freedom to design and expand clinical services based on patient needs, and to tailor systems to manage the operations unique to the programs. A critically important aspect of Institute support also had to do with fostering a sense of program ownership and an entrepreneurial approach such that, as long as a program could advance in areas of research, training and clinical excellence, and be fiscally responsible, leaders of the program had a large degree of discretion to make program adjustments as needed. This bottom-up approach, not often typical of either hospital or university medical school cultures, allowed the Neurobehavioral Programs (and several other programs and clinics at Kennedy Krieger) to flourish. The COVID-19 pandemic presented us with many challenges, but affirmed it is possible to adapt while also remaining on course. Adapting to change is necessary for any entity to survive, but the mission to integrate clinical service, research, training, and advocacy in itself has proven to be an engine for change that will continue to guide us into the future.

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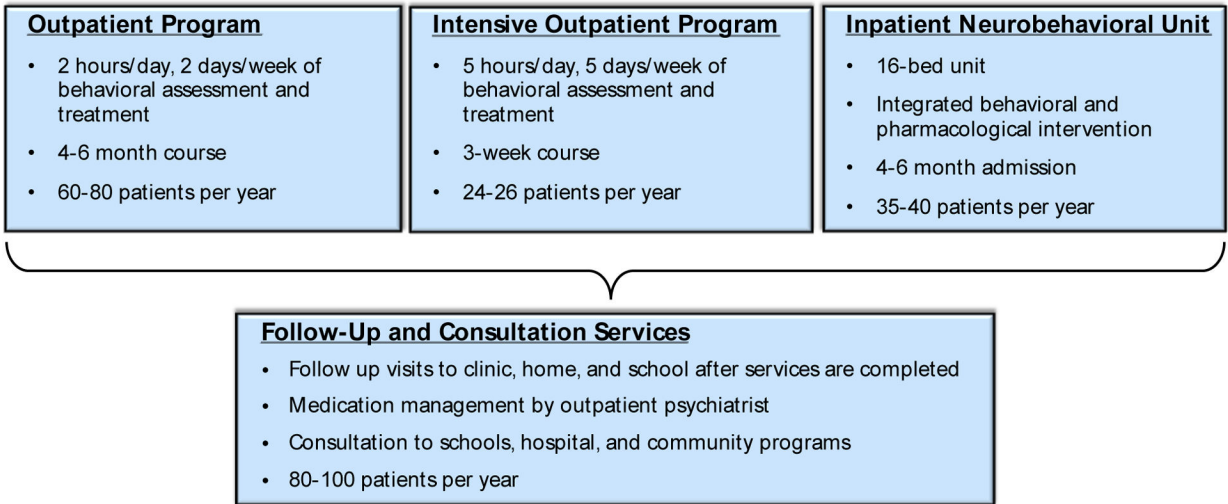
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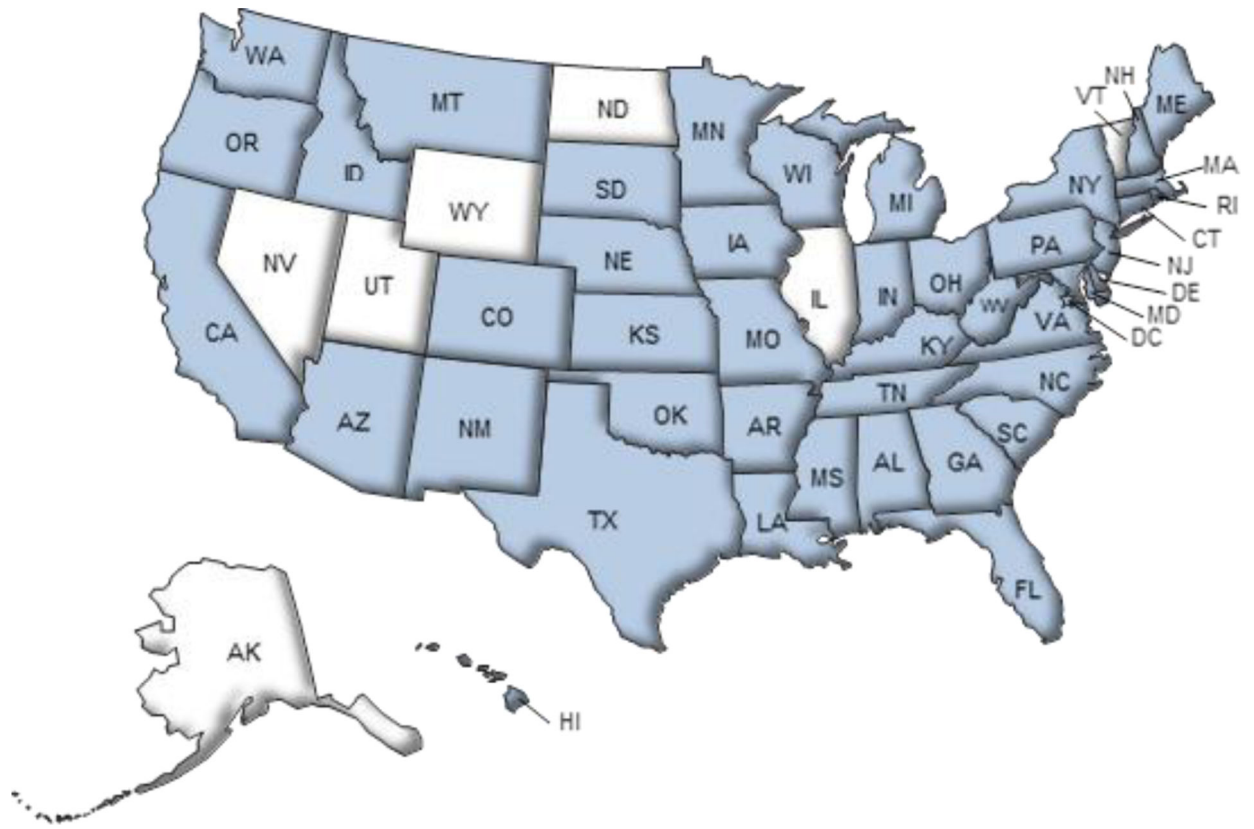
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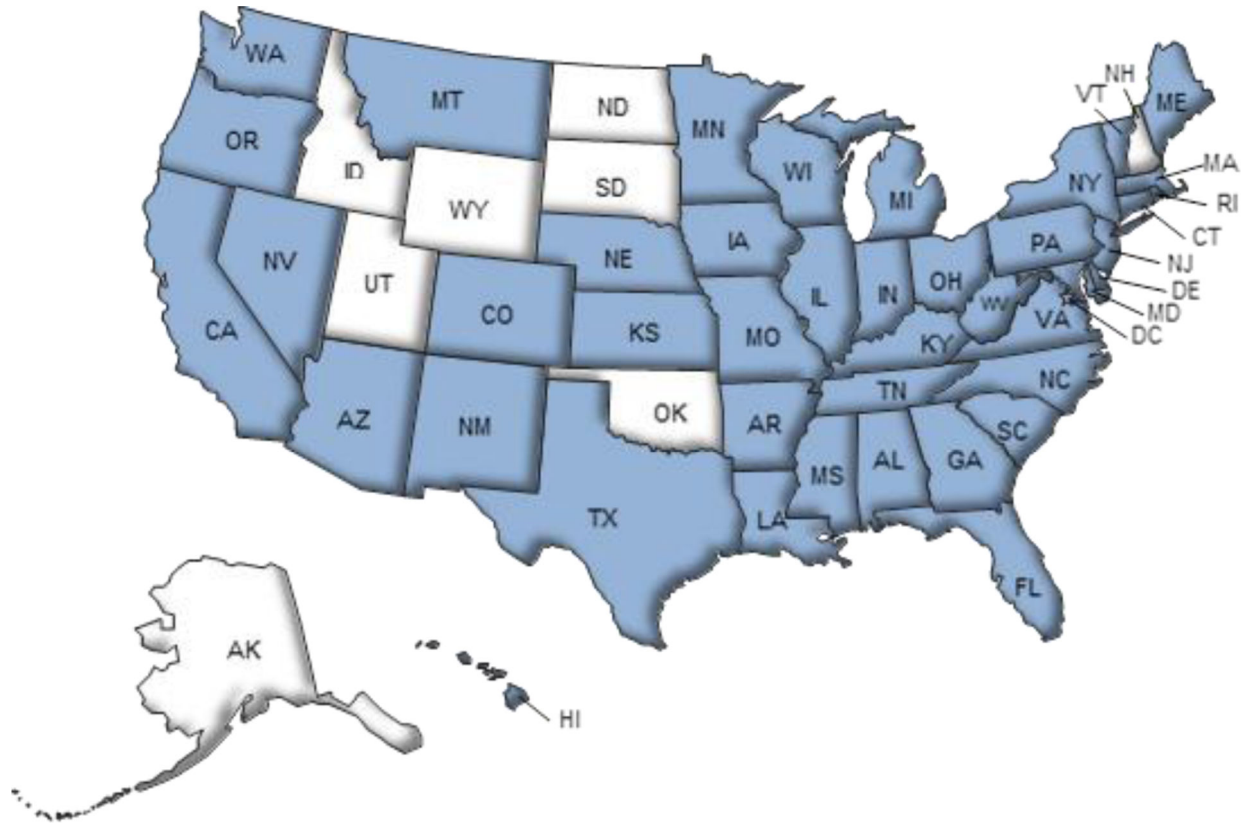
# Neurobehavioral Continuum of Care



**Figure 1.**  
Neurobehavioral Continuum of Care.



**Figure 2.**  
States from which patients have been served by the Neurobehavioral Programs.



**Figure 3.**  
States in which former staff and trainees currently practice.