

START is a research-based model of community-based crisis prevention & intervention services for individuals age 6 and older with intellectual and developmental disabilities and mental health needs. START was first developed in 1988 by Dr. Joan B. Beasley and was cited as a model program in the 2002 US Surgeon General's report on mental health disparities for people with IDD.

The **Center for START Services (CSS)** at the UNH Institute on Disability/UCED is an organization of experts in the mental health aspects of IDD who develop innovative MHIDD training programs, conduct research, and facilitate the development of START programs across the country.

Institute on Disability/UCED



Disparities Among People with IDD and Mental Health Needs

- People with IDD experience numerous health disparities, including higher rates of mental health symptoms and behavioral challenges, compared to their typically developing peers.^{1,2}
- These difficulties are often misdiagnosed, under-diagnosed, or undiagnosed, and even when detected, few evidence-based treatments exist.^{3,4}
- This gap has translated into use of costly and ineffective care, resulting in frequent emergency department and psychiatric hospital visits,^{5,6} poorer quality of life, and earlier age of mortality^{7,8} for individuals with IDD.

Positive Outcomes

Health and service data on all individuals enrolled in START programs are entered in a central database and analyzed to measure outcomes and trends. **Across the US, individuals enrolled in START have shown improvements in several key outcome measures including:**

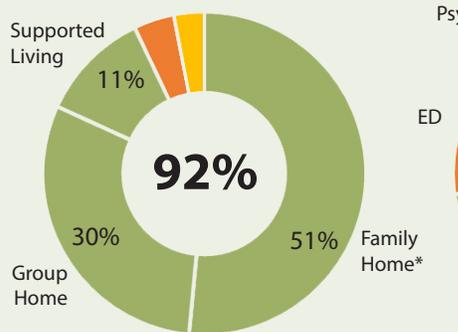
High rates of stabilization following crisis

73% of the 3,000 crisis contacts in FY19 resulted in individuals remaining in their current community-based setting, avoiding potential ED visits and/or psychiatric inpatient admissions.

Reduced psychiatric hospitalization and ED usage

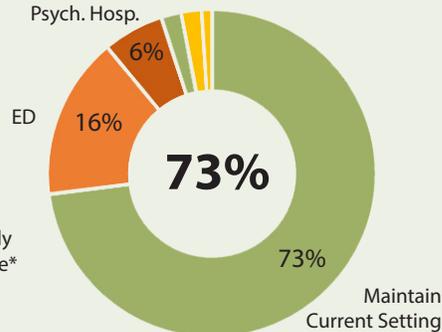
Children and **adults** enrolled in START programs visit the emergency department less and have fewer psychiatric hospitalizations than they did in the 12 months prior to receiving START services.

92% of START service users live in the community

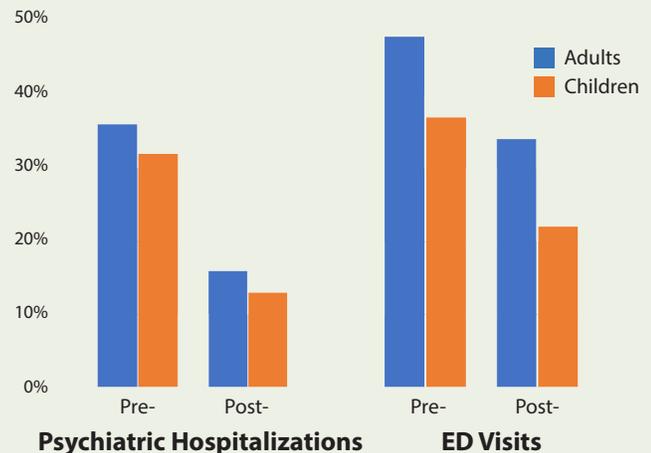


*includes Alternative Family Living and foster care

73% of crisis contacts result in stabilization in current setting



Changes in Emergency Service Utilization Pre- and Post- START Enrollment



Research Cited

- Cooper, S. A., Smiley, E., Morrison, J., Williamson, A., & Allan, L. (2007). Mental ill-health in adults with intellectual disabilities: prevalence and associated factors. *The British Journal of Psychiatry*, 190(1), 27-35.
- Deb, S., Thomas, M., & Bright, C. (2001). Mental disorder in adults with intellectual disability. 1: Prevalence of functional psychiatric illness among a community-based population aged between 16 and 64 years. *Journal of Intellectual Disability Research*, 45(6), 495-505.
- Peña-Salazar, C., Arrufat, F., Santos, J. M., Fontanet, A., González-Castro, G., Más, S., Roura-Poch, P. & Valdés-Stauber, J. (2018). Underdiagnosis of psychiatric disorders in people with intellectual disabilities: Differences between psychiatric disorders and challenging behaviour. *Journal of Intellectual Disabilities*
- Krahn, G. L., Hammond, L., & Turner, A. (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *MR and DD research reviews*, 12(1), 70-82.
- Kalb, L. G., Beasley, J., Klein, A., Hinton, J., & Charlot, L. (2016). Psychiatric hospitalisation among individuals with intellectual disability referred to the START crisis intervention and prevention program. *Journal of Intellectual Disability Research*, 60(12), 1153-1164.
- Kalb, L., Stuart, E., Freedman, B., Zablotzky, B., & Vasa, R. (2012). Psychiatric-related emergency department visits among children with an autism spectrum disorder. *Pediatric Emergency Care*, 28(12), 1269-1276.
- Lauer, E., & McCallion, P. (2015). Mortality of people with intellectual and developmental disabilities from select US state disability service systems and medical claims data. *Journal of Applied Research in Intellectual Disabilities*, 28(5), 394-405.
- Nota, L., Ferrari, L., Soresi, S., & Wehmeyer, M. (2007). Self-determination, social abilities and the quality of life of people with intellectual disability. *Journal of Intellectual Disability Research*, 51(11), 850-865.

For more information please contact Luke Reynard, Director of Operations at lucas.reynard@unh.edu or (603) 228-2084 ext 56

Service System Resource Analysis

A service system resource analysis is a comprehensive, data-driven approach to identifying a system's strengths and areas for improvement - it is a critical first step in evaluating a service system's ability to meet the needs individuals with MHIDD and improve overall quality of life for those individuals and their families.

- **METHODS** - data collection involves a variety of methods including focus groups, online surveys, and family member interviews
- **RESULTS** - final report includes quantitative and qualitative analysis, overall themes, and recommendations

A resource analysis can lead to a variety of solutions tailored to a service system's needs including, but not limited to, the development of discipline-specific professional development training, professional learning communities (PLCs), and full START program implementation.

The START Model

The START Model is a crisis prevention and intervention research-based cross systems program serving ages 6 to adults and their families. Members of the CSS national team assist START programs in each location with their START program design, training and tools of the model, on-going evaluation of outcomes, technical support and best practices in MH aspects of IDD. START teams across the country work together as a national community of practice facilitated by the national Center for START Services. START programs have been developed in 15 states across the U.S with a goal of positive systems change in each location.

Certified START programs offer:

- Expertise in the mental health aspects of IDD
- Validated assessments, training, interventions, and ongoing dialogue with stakeholders within the context of the START model's guiding principles
- Therapeutic coaching, clinical evaluation and crisis beds
- Outreach to the person, their supports and service providers to enhance capacity of all
- Provide face to face and timely crisis prevention and intervention services 24hr/7day crisis response
- increase knowledge of MHIDD among professionals through outreach & training
- Participate in CSS innovative training and research initiatives



Professional Development

CSS provides a variety of training programs for professionals that serve individuals with MHIDD.

START National Online Training Series

Annual online series of 6-8 trainings designed to provide innovative and topic-focused training to professionals that serve individuals with MHIDD.

START National Training Institute (SNTI)

Annual in-person training event hosted by CSS. The SNTI brings together hundreds of START team members, self advocates, families, and national & international leaders in the field of MHIDD to share expertise, tools, and best practices. The training spans two and a half days and features keynote addresses, panel discussions, breakout sessions from content-focused strands, a research poster symposium, and after-hours events.

Professional Learning Communities (PLC)

START PLCs provide professionals from various disciplines with expert training, facilitated discussions, and evidence-based approaches & tools to improve overall knowledge of MHIDD across a local or regional system of care. Topics/focus areas include:

- MHIDD for MCO Care Coordinators
- Integrated Health and MHIDD for health providers
- Therapeutic Coaching & Supports for DSPs
- START Programmatic Overview for Community Stakeholders

Research & Evaluation

The SIRS Database

CSS developed and maintains the START Information Reporting System (SIRS), a database utilized by all START programs that collects demographic, clinical and service outcomes for every person that has been or is currently enrolled in a START program.

National Research Consortium on MHIDD

CSS established the National Research Consortium on MHIDD to advance research on best practices and policy changes that promote positive outcomes among individuals with MHIDD.

MHIDD Training for Mobile Crisis Responders

6-week web-based training course designed for mobile crisis responders who support individuals with IDD and mental health needs. The course teaches best practices in crisis assessment, response, and disposition and is highly recommended for the following providers:

- Mobile Crisis Responders, Clinicians & Supervisors
- Mental Health and/or IDD Case Managers/Service Coordinators
- Emergency Service Clinicians