Implementation of the HANDS in Autism® coordinated care continuum: Changes in caregiver-reported patient problem behavior presence and intensity secondary to the implementation of HANDS in Autism® Model across home and school settings following acute inpatient hospitalization

Aditi Deodhar[1], Tiffany Neal[1], Archana Darsanapu[1], Naomi Swiezy[1]

[1]HANDS in Autism® Interdisciplinary Training and Resource Center, Department of Psychiatry, Indiana University School of Medicine

Abstract

HANDS in Autism® provides follow-up services for adolescents (12-18 years old) with autism spectrum disorder (ASD)/developmental disorders (DD) as they transition back to their home communities following acute inpatient hospitalization. HANDS focuses on training and the facilitation of community teams for sustainable outcomes in coordinated care using the HANDS in Autism® Model, a comprehensive training framework rooted in evidence-based practices. The primary driver and target of the intervention is families within the home setting, with supported training for school/community teams. The aim of this study was to explore changes in patients' problem behaviors within the home and school settings. Caregivers and school teams completed the Home Situation Questionnaire (HSQ) and School Situation Questionnaire (SSQ) where they reported the presence and intensity of patient problem behaviors during daily situations prior to admission on the stabilization unit and the year following discharge while receiving HANDS services. Preliminary results indicate the presence and intensity of problem behaviors decreased from pre-admission to post-discharge in both home and school settings. The intensity of problem behaviors steadily decreased throughout the 12-month post-discharge period within the home setting, suggesting the HANDS coordinated care continuum supported continued improvement within the primary target of the intervention. In contrast, the intensity of problem behaviors showed some increase in the school setting at the 12-month mark. The effectiveness of the intervention in school settings may be impacted by the level of engagement by school personnel/districts.

Background

Approximately 17% of Indiana's population has autism spectrum disorder (ASD) or other developmental disabilities (DD) that require professional intervention and community support (Zablotsky et al, 2019). Twenty percent of the non-disabled Indiana residents are caregivers for individuals with disabilities (AARP and National Alliance for Caregiving, 2020). Adolescents with ASD or DD are more likely to exhibit persistent problem behaviors such as aggression or self-injurious behavior in multiple settings (Mathesis et al., 2021), contributing to higher levels of caregiver stress (Patel et al., 2022). Further, less than 20% of treating providers and teams in the state have specific disabilities training, with more than half feeling inadequately prepared to provide treatment (Ryan & Scior, 2015).

The HANDS in Autism® Interdisciplinary Training & Resource Center helps address these gaps in service and training by providing research-based practical training and support to stakeholders including families, school staff, medical professionals, community providers, and justice and law enforcement personnel for them to best support individuals with ASD or DD. The training and support are rooted in the HANDS model which emphasizes the understanding and implementation of empirically supported practices with fidelity in community-based settings. HANDS in Autism® has partnered with an acute stabilization unit to provide the follow up services for the patient's transition, integration and long-term success within the natural environment. The HANDS coordinated care continuum focuses on identifying and meeting community needs and fostering collaboration and sharing of information across systems to facilitate building and sustaining capacity.

Research Hypothesis

It is hypothesized that patient problem behaviors will exhibit reduction from prior to admission to the one year following discharge in both the home and school settings, demonstrating the efficacy of the HANDS in Autism® coordinated care continuum following discharge from acute inpatient hospitalization.

Materials and Methods

Participants: Participants included team members from the home (n=104) and school (n=58) systems for patients admitted to the Adolescent Advanced Unit at the NDI Advanced Treatment Center and followed by HANDS in Autism one year post discharge.

Measures

Home Situation Questionnaire (HSQ; Barkley and Edelbrock, 1987; Barkley et al., 1999)

The presence and intensity of patient problem behaviors in the home setting were assessed with the HSQ. This measure consists of 27 items describing daily situations such as basic hygiene, social activities, and routines. Respondents indicate whether the patient has problem behaviors during these daily situations and, if yes, the severity of problems on a 9-pont Likert scale (1=Mild severity, 9=Significant severity). Respondents completed the HSQ prior to admission (pre-admission), as well as 1-week, 1-, 3-, 6- and 12-month post discharge.

School Situation Questionnaire (SSQ; Barkley and Edelbrock, 1987)

The presence and intensity of patient problem behaviors in the school setting were assessed with the SSQ. This measure consists of 21 items describing daily situations such as lecture/class instruction, class breaks/lunchtime and follows the same directions and scales as the HSQ. Respondents completed the SSQ prior to admission (pre-admission), and 1-and 12-month post discharge.

Procedures: All responses were primarily recorded via online survey and respondents were also provided alternate options of completing a paper survey or verbally giving responses over the phone if they did not have reliable internet access. There was attrition at post discharge timepoints due to lack of response or early withdrawal from services (see Table 1). Data was securely collected and managed using the Research Electron Data Capture (REDCap) hosted by Indiana University (Harris et al., 2009).

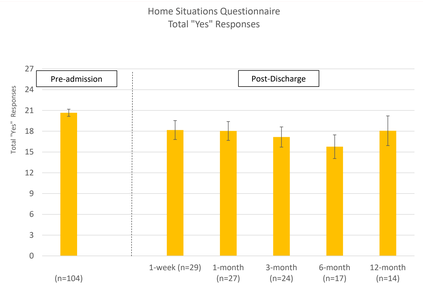
Table 1: Number of Respondents per Timepoint

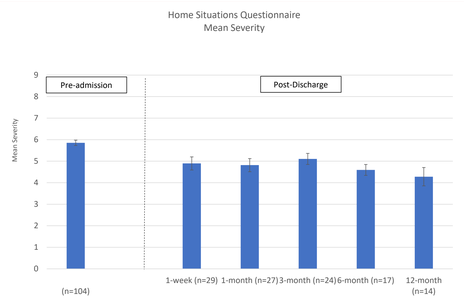
Timepoint	HSQ (n)	SSQ (n)
Pre-admission	104	58
1-week post discharge	29	N/A
1-month post discharge	27	19
3-month post discharge	24	N/A
6-month post discharge	17	N/A
12-month post discharge	14	5

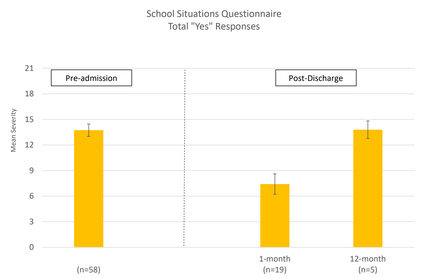
Results and Findings

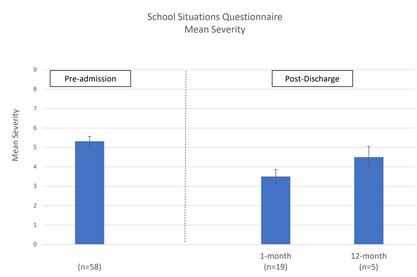
Preliminary repeated-measures ANOVAs were conducted to examine the effect of timepoint on either the total "yes" responses or mean severity for both home and school settings. The total "yes" responses marginally changed over time in the home setting ($F(5,25) = 2.13, p=0.09$) and significantly changed over time in the school setting ($F(2,2)=23.33, p=0.03$). The mean severity significantly decreased over time in the home setting ($F(4,20)=3,52, p=0.02$) and changed marginally over time in the school setting ($F(2,2)=13.94, p=0.07$).

Note: Error bars reflect standard error









Conclusions and Future Directions

The presence of problem behaviors marginally fluctuated in the home setting and significantly fluctuated in the school setting. This variability is not entirely surprising since other factors (e.g., parent/sibling illness, family financial issues, school resources) could have impacted the fidelity of implementation of empirically supported practices.

The intensity of problem behaviors did significantly decrease in the home setting from pre-admission and during the year following discharge, suggesting that the follow-up services supported the transition and integration of patients back into their home setting.

The intensity of problem behaviors marginally changed within the school setting with an initial reduction at the one month following discharge and some increase (but still lower than pre-admission levels) at the 12-month timepoint. While this suggests some improvement within the school setting, indication of problem behaviors following discharge is limited by fewer data points. Other factors such as school personnel/district engagement could also impact progression within the school setting.

To address some limits of the data, the research team is focused on a couple of improvement efforts: (1) improving processes to increase response rates on measures (e.g., providing hardcopies or assistance from HANDS team member) and (2) determining strategies to maintain family and community team engagement in the data and implementation of empirically supported practices.

Future directions are focused on combining the current data with other measures that assess the implementation of specific strategies aimed to reduce problem behaviors and overall patient functioning across different life domains (e.g., self-care, social communication). This will allow for a more complete understanding of the patient's progress and tailor ongoing interventions as patients transition and integrate into their family and community settings following discharge.

CONFLICT OF INTEREST: The Authors have no conflicts of interest to declare.

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