ABSTRACT
It is the mission of START to improve not only the lives of individuals served, but also the lives of their families, in addition to keeping families together in the community. Indeed, 64 percent of individuals enrolled in NYSTART Region 5 reside with their families. Given the severity of behavioral health symptoms of individuals referred for START services and the potential impact on the family with respect to caregiver burden, it is important to consider the family’s access, inclusion and satisfaction with care. We examined the relationships among caregiver satisfaction, natural supports, difficulty caring and outcome measures including severity of behavioral health symptoms as well as emergency service use. To this end, data from the Family Experiences with Mental Health Services for Persons with Intellectual and Developmental Disabilities (FEIS) was utilized and the number of positive, natural supports was tallied from the intake ecomap. Data from the SIRS database including the Aberrant Behavior Checklist (ABC), the Recent Stressors Questionnaire (RSQ), and emergency service use served as outcome measures. It was our hypothesis that positive family experiences with providers and more positive natural supports in a system would relate to more positive outcomes for the individual. Family involvement and satisfaction with mental health providers and positive, natural supports are important in guiding the START coordinator’s collaboration with the system to effect a positive change in behavioral health symptoms and to help ensure the individual’s success and inclusion in the community.

FINDINGS

Satisfaction and Accessing Services

• 56% of caregivers had some degree of difficulty accessing services
• 45% reported some degree of dissatisfaction with MH services
• 86% reported considerable difficulty caring for their loved one
• Degree of difficulty in caring is associated with increases in ABC scores.
• Regardless of level of difficulty in caring, elevations in the ABC Irritability and Hyperactivity subscales were consistently noted

Natural Supports and Caregiver Burden

• There is no clear association between number of natural supports and degree of difficulty in caring
• 41% indicated that providers showed little to no recognition of caregiver burden

Difficult Caring

DISCUSSION

Originally we hypothesized that a higher level of family satisfaction with mental health services would be associated with fewer behavioral health symptoms for the individual and less reliance on emergency service use. However, there was no clear pattern or trend indicated within our sample size of 71 cases. What did emerge, based on data garnered from the FEIS, was that increased difficulty caring consistently was associated with elevations in irritability and hyperactivity on the ABC as well as increased emergency service use. Notable was that 86% of our informants had considerable difficulty caring for their loved one, but 56% had difficulty accessing mental health services and 45% reported some degree of dissatisfaction with those services. Clearly, further work is necessary to bridge gaps in communication, establish additional linkages and continue efforts in providing education within the larger system on Long Island. The fact that certain hypotheses were not supported may be a function of variability seen in data from the FEIS, where, for example, in spite of as many as nine instances of emergency service use, some caregivers reported only slight difficulty in caring for their loved one and were satisfied with mental health treatment. Likewise, we observed numerous responses of “did not know/answer” within the questions related to family inclusion, potentially related to families not being aware of appropriate treatment and the importance of their role in mental health services. Nonetheless, the majority of caregivers were encouraged to take an active role in their loved one’s treatment. However, that 39% received little to no encouragement to do so is striking and again points to the need in facilitating more positive and inclusive interactions with mental health providers. The findings point to the need for intensive systems work in order to support families having a role and being heard by the providers treating their loved ones. Perhaps most surprising was the finding that there was no clear association between the number of natural supports for the caregiver or the individual on the degree of difficulty caring or severity of behavioral health symptoms/emergency service use. This was unexpected, and could be related to the quality of those natural supports that are indicated on the ecomap. It is important to recognize the burden of the caregiver so this can be addressed. Going forward, additional linkages and improved relationships with mental health providers should be highlighted through increased community training opportunities and expanding the attendance of mental health providers at Clinical Education Teams (CET) so as to build capacity in the community. At a systems level, coordinators should emphasize bridging gaps in communication between providers and families. In addition, more direct measures of caregiver burden should be explored to allow for more direct assessment and support of the caregiver to ensure their inclusion and engagement in services, as well as to more effectively address their needs. Moving forward, Region 5’s focus on these areas will be imperative not only to improve the care and support of individuals and their systems, but also to build capacity in the larger community system as whole.

REFERENCES


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