



SELF-DIRECTED CARE AUTISM REINVESTMENT PROGRAM

Magellan Behavioral Health of Pennsylvania

Parents of children with autism experience tremendous stress and numerous obstacles as they attempt to support and care for an autistic child. The Self-Directed Care (SDC) Autism program in Pennsylvania addressed these challenges in an innovative way. Families had the opportunity to collaborate with an SDC coach to manage a \$2,500 budget for the purchase of goods and services not covered by insurance or existing community resources corresponding to their specific resiliency goals.

Magellan Health Services partnered with NHS Human Services Lehigh Valley Center and Elwyn ARCH of the Lehigh Valley to implement this program, for which community reinvestment funds of \$390,000 were secured.

Participants

The SDC Autism program, implemented in 2010-2011, was comprised of 144 families with 158 children (including 14 pairs of siblings) with a diagnosis along the autism spectrum. The children were between the ages of 2 to 22 years old, and 124 of the 158 (78 percent) were male.

The families completed applications and were admitted into the SDC program based on residence in Lehigh County and diagnosis on the autism spectrum. The families worked with an SDC coach individually from either NHS or Elwyn.

Pennsylvania Participants in the Self-Directed Care Autism Program

Total Number	158 children from 144 families (including 14 pairs of siblings)
Female	34 of 158 children
Male	124 of 158 children
Age Range	2 – 22 years old

Potential Success Indicators Tied to Program Goals

Based on program goals of enhancing resiliency, improving functioning, remaining cost-neutral and attaining high program satisfaction, the following measures were identified as potential success markers for the SDC program:

- Goal attainment scale
- Self-directed expenditures
- Autism Treatment Evaluation Checklist (ATEC)
- Satisfaction

A decision was made to use the Autism Treatment Evaluation Checklist, because it is strengths-based and applies directly to the child's functioning. The ATEC also was available without charge through Web-based access from the Autism Research Institute (www.autism.com).

Goal Attainment

By the end of the program, 44 percent of the children showed improvement on at least one goal. High goal achievers continued the program at least three quarters.

Self-Directed Expenditures

The SDC coach worked diligently with each family to identify resources available in their communities, and to help them prioritize all viable options to maximize the benefit of the SDC funds. The SDC coach also effectively obtained access to existing relevant community resources for all families, including scouting and driving lessons.

By the end of the program, the families spent just over the \$390,000 budget for SDC expenditures tied to goals. The top three categories were activities (\$152,577), computer/media (\$128,048), and sensory/gross motor equipment (\$31,230). Interestingly, respite was not the most popular category of expenditures.

Autism Treatment Evaluation Checklist (ATEC)

An expected benefit of the use of self-directed care funds was improvements in functioning related to autism. The ATEC is a tool with demonstrated sensitivity to treatment change for children with autism. The checklist contains 77 items under four scales:

- I. Speech/Language/Communication
- II. Sociability
- III. Sensory/Cognitive Awareness
- IV. Health/Physical/Behavior

The total score for improvement ranged from six percent to 12 percent, at the time intervals of three, six, nine and 12 months in the program. Each interval showed statistically significant improvement in functioning.

Satisfaction

Satisfaction was formally assessed at discharge by a brief self-report. At discharge, families reported that they were highly satisfied overall, with a score of 18.2 out of a possible total score of 20. The four satisfaction questions were:

Question	Satisfaction Score
My child is making the progress I expect as a result of participation in the Self-Directed Care program.	4.5/5
We are being provided with the level of care coordination I expect as a result of participation in the Self-Directed Care program.	4.6/5
We have made improvement in family goal areas as a result of participation in the Self-Directed Care program.	4.5/5
Services are provided in a timely, professional and responsive manner.	4.5/5
Total Satisfaction	18.2/20

When given the opportunity to provide open-ended feedback, many parents described improved well-being, quality of life and value regarding the positive impact of SDC expenditures across multiple domains. Despite the chronic issues facing their children, many parents reported that the program provided a great benefit to their family. For example:

- “I think this is a wonderful program because it allows families to purchase important services that help autistic children become independent and aware of their surroundings.”

- “The program was able to provide resources that helped [my son] progress at an increased pace. The purchase of technology [a computer] has assisted in his learning more communication skills at a more rapid pace.”
- “I enjoyed working with the agency with this grant. It helped my family do things we wouldn’t be able to do. My family has made some improvements and is able to enjoy doing more in the community.”
- “Our coach was extremely helpful getting us started with the program. He is professional, courteous and responsive! It has been a positive experience!”
- “Our coach was informative, knowledgeable, empathetic and experienced.”

Conclusion

The Self-Directed Care program reached success on the levels of satisfaction, choice of self-directed funds, goal attainment and improved functioning. Self-directed care allows the opportunity to learn what is valued and desired from participants.

In this program, the top three self-directed expenditure categories were activities, computer/media and sensory/gross motor equipment, and most families spent all available self-directed funds. The fact that 33 percent of the funds went toward computer/media may signal a growing interest in using computer/media to attain goals and could be further explored.

Forty-four percent of the children showed improvement on at least one of their goals as rated by their SDC coach on the Goal Attainment Scale. Functional improvement as demonstrated by the ATEC change scores in a relatively short period of time is noteworthy, particularly in light of the chronic nature of autism.

For those involved in the project, we acknowledge their pioneering work and efforts.

*www.autism.com, Autism Research Institute website <http://autism-nutrition.com/autism-treatment-evaluation-checklist-atec>