

Replicable Programming: Disabilities Services

Agency: Jewish Family and Children's Service of Greater Philadelphia (JFCS)

Agency Budget: \$12,858,890

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Staff Listing (program specific):

Eli Schostak: Director of Individual and Family Services

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Summary:

In December 2014, JFCS was awarded \$25,000 by Autism Speaks' Family Services Community Grant to develop a Quality of Life (QoL) instrument for Adults with Autism Spectrum Disorder (ASD). JFCS recognized the difficulty for providers in identifying and meeting the multifaceted needs of this priority population without a reliable tool.

Following a literature review, focus group, interviews with adults with ASD, two versions (employed and unemployed) of The Quality of Life Assessment for Adults with ASD (QLAA) were piloted. The results were overwhelmingly positive; plans are in place to finalize and disseminate the tool and manual for use in the field.

The QLAA includes the six domains that incorporate individuals' values, aspirations and current life circumstances. Professionals (care managers, vocational rehabilitation specialists, psychologists, care coordinators and social workers in residential, day habilitation and other settings) will now be able to: determine client needs during the initial assessment; review progress; inform strategy; evaluate service appropriateness; evaluate intervention effectiveness; and develop meaningful treatment plans. Furthermore, aggregate data may lead to vital macro level policy changes.

The QLAA is undoubtedly a contribution to the field of Autism service provision. In 2016, the project will expand to include a larger sample and collaboration with more service providers.

Total Program Cost and Funding Sources: \$25,000 Autism Speaks' Family Services Community Grant

Link pertaining to the program or video as part of the strategy:

<https://www.autismspeaks.org/family-services/grants/community-grants/2014>

List of 3 major outcomes and evaluation method(s) used to determine those outcomes:

1) Development of an appropriate Quality of Life Assessment for Adults diagnosed with ASD (QLAA).

The QLAA was developed by incorporating existing theories and models of quality of life, the views and recommendations of experts in the field, and the input of adults with ASD.

2) Sensitivity of the QLAA: Follow up interviews were completed to test the sensitivity of the QLAA.

Adults completing a follow up interview were asked if there were any significant changes in their lives since the first interview. Reported changes were documented, and later reviewed when comparing the two interview scores for each participants. The QLAA appears to detect changes within each of the six domains.

2) Use of Proxy Interviews: When comparing the proxy results to the results of the adult with ASD, the family members' scores did not vary greatly from the adults' scores. These results indicate that family members may be a reliable source in determining an individual's quality of life, which is useful if the tool cannot be administered directly with the adult due to communication impairments. The most accurate information about one's quality of life, is that which was provided by the individual being assessed. However, based on a comparison of the participants' scores and the proxy scores reviewed, it can be concluded that individuals who are greatly involved in an individual's life could be complete a proxy QLAA and assist in determining the individual's quality of life.