

Assessing Quality of Life in Undergraduate Students with Developmental Disabilities Enrolled in the University of Cincinnati Transition and Access Program

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Disclosures

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 Post-secondary education is a developmental task of adulthood that has become increasingly accessible to individuals with developmental disabilities (DD)

 Has positive effects in areas such as independent living, social interaction, and employment skills



- Transition from high school to adulthood can have a profound impact on Quality of Life (QOL)
- Quality of Life is individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns.



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- Increasing number of post-secondary education programs available for individuals with DD
- Supportive social networks and local supports
 - Positive impact on Quality of Life
 - Lead to successful adult outcomes



- We know little about how the participation of individuals with DD in postsecondary education affects their quality of life (QOL)
- Some studies in young adults with Autism in post-secondary courses
- Significant symptoms of anxiety, loneliness and depression and lower QOL
- Lack of data for QOL in adults with other developmental disabilities
- Impact of post secondary education on QOL and adult outcomes.



Study Objectives

 Examine various aspects of QOL in UC TAP students using both questionnaires and individual semi-structured interviews.

 Examine how QOL measures are related to individual, environmental, and UC TAP program factors



University of Cincinnati Transition and Access Program (UC TAP)

- 4-year
- Non-degree undergraduate program
- Mild to moderate intellectual disabilities
- Postsecondary experience on a college campus to achieve success with appropriate supports
 - Inclusive college classes
 - Professional internships
 - Active social life
 - Campus housing



Methods

- Participants: Undergraduate students in the UC TAP Program
- Procedure: Administer QOL surveys and conduct brief, individual interviews on the UC TAP student's perspective/ thoughts on their QOL

Tools:

- Interpersonal Support Evaluation List (ISEL)*
- Semi-Structured Interview
- WHO QOL- BREF



Outcomes



Analyses

 Individual interviews: audio recorded, transcribed, and manually coded

- Statistical Analysis SPSS 20.0
 - WHOQOL- BREF
 - Interpersonal Support Evaluation List



Sample Characteristics (N = 23)

Characteristic	
Mean Age, in years	22.6 (<u>+</u> 3.9)
Male, n (%)	11 (48 %)
Mean IQ (Std. Deviation)	70 (<u>+</u> 17)

Diagnoses	n
Autism Spectrum Disorder	9
Cerebral Palsy	1
Down Syndrome	3
Intellectual Disability	4
Learning Disability	1
Emotional Disturbance	2
Other Genetic Disorders	3



What is Quality of Life?

Majority – I don't know

"Quality of life means to me, like the way I am living is something that I am like proud of, I really enjoy, even though I might have really big struggles sometimes, I still can get through it because I have a great support system that I can always go to for help"

- TAP student



WHOQOL-BREF

Quality of Life Domain	Mean Score	Std. Deviation
Physical Health	61*	14
Psychological	67	12
Social Relationships	64*	27
Environment	75	17

- Range of standard scores: 20-100
- Higher scores mean better health



Top 3 Quality of Life Domains





Key Themes

- Valued physical health and well being
- Being happy and feeling good about themselves
- Feeling supported by family
- Friendship is important; friends are valued
- Interactions with TAP staff mostly positive
 - supportive during crises
 - problem solving



Key Themes

- Stress was universally reported
- Multiple stressors
- Academic work/ exams
- Conflict with room mates
- Time management (study and leisure)
- Conflicts in family (outside of TAP)
- Underlying mental health illness
- Emerging coping skills



Key Themes

- Rights treated equally and respected
- Social Inclusion both in TAP program and UC community

"For the first time, I feel like I fit in and this is a huge thing because I have never felt like that"

TAP student



Self Determination & Personal Development

- Self determination goals for future emerging
- Living independently or with roommates
- Activities of daily living (cooking, laundry)
- Managing personal health
- Self advocacy
- Becoming financially independent
- Time management and coping with stress
- Academic success (getting good grades)



Conclusions

- Young adults with DD perceived lower quality of life in physical health and social relationships
- Self determination was an important emerging theme
- Emotions and stress emerged as a key theme and concern
- Student experiences also very typical of challenges encountered in college life



Limitations

- Small sample size
- Results specific to UC TAP program, not all post-secondary education program have the same model
- Other factors* impacting quality of life
- Timing of interviews during the semester influenced responses



Future Steps

 Assess which specific support characteristics predict better adult outcomes

- To develop specific supports to help students cope with their stress and improve quality of life
- Assess for change in QOL over time (at the beginning of program vs. towards the end)



Thank you!



Questions?



References

- Chiang, H. M., Cheung, Y. K., Li, H., & Tsai, L. Y. (2013). Factors associated with participation in employment for high school leavers with autism. *Journal of Autism and Developmental Disorders*, *43*(8), 1832-1842. doi: 10.1007/s10803-012-1734-2
- Gelbar, N. W., Smith, I., & Reichow, B. (2014). Systematic review of articles describing experience and supports of individuals with autism enrolled in college and university programs. *Journal of Autism and Developmental Disorders*, *44*(10), 2593-2601. doi: 10.1007/s10803-014-2135-5
- Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome: a brief report. *Autism*, 10(4), 403-414. doi: 10.1177/1362361306064432
- Papay, C. K., & Bambara, L. M. (2011). Postsecondary education for transition-age students with intellectual and other developmental disabilities: A national survey. *Education and Training in Autism and Developmental Disabilities*, 78-93.
- Renty, J. O., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, *10*(5), 511-524. doi: 10.1177/1362361306066604
- Schalock, R. L., Brown, I., Brown, R., Cummins, R. A., Felce, D., Matikka, L., . . . Parmenter, T. (2002). Conceptualization, measurement, and application of quality of life for persons with intellectual disabilities: report of an international panel of experts. *Mental Retardation, 40*(6), 457-470. doi: 10.1352/0047-6765(2002)040<0457:CMAAOQ>2.0.CO;2
- WHOQOL Group. (1995). The World Health Organization quality of life assessment (WHOQOL): position paper from the World Health Organization. *Social Science and Medicine*, *41*(10), 1403-1409.

