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Fostering Community Participation for Youth with Intellectual and Developmental Disabilities: An Occupation-Based Program for Caregivers

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BACKGROUND

Youth outcomes are associated with caregivers' limited knowledge, access to information on higher education, and uncertainty when it comes to caregivers' expectations of employment, education, and living situations in adulthood (Codd & Hewitt, 2020; Kirby, Holmes et al., 2020; Kirby, Holmes et al., 2021).

Occupational therapists treat caregivers with youth with intellectual and developmental disabilities, but literature demonstrates few programs were facilitated by occupational therapists (Rosner et al., 2020).

PROBLEM

Caregivers of youth have unrealistic expectations for their youth with intellectual and developmental disabilities as they assume greater independence in community participation (Francis, Stride, & Reed, 2018; Hoffman & Kirby, 2021; Kirby, Diener, et al., 2021; Warren et al., 2021)

PURPOSE

The purpose of this program development capstone project is to develop an occupation-based program focused on caregiver expectations to promote independence in community participation in transition-aged youth with intellectual and developmental disabilities (Francis, Register, and Reed et al., 2018; Ho et al., 2018).

Project objectives:

1. Conduct a needs assessment of site resources for caregiver support using SWOT analysis
2. Develop assessment of program
3. Create and implement a 6-week program to increase expectations of caregivers of youth that assume greater independence in community participation
4. Have participants fill out program evaluation questionnaires at the end of each program to evaluate program effectiveness

METHODS

Setting: Adult Transition Program in San Marcos, California

Participants:

- Caregiver and youth pairs –
- Caregivers of youth with intellectual and developmental disabilities
 - Youth between 14-24 year's old
 - Speaks and understands English
 - Must have a reliable electronic device to access the program's online platform

Assessment Tools:

- SWOT Analysis
- 5- question program evaluation form provided during the end of each session

Development and Implementation:

- Potential participants identified by the site supervisor as candidates who would be the most receptive and gain the most benefit from the program outlined
- A program flyer dispensed to selected and eligible participants
- Program held for 6 weeks, 1x a week for max 1- hour sessions
- Activity, discussion, program evaluation form

Program outline each week:

- 1) Youth identify their interest's and hobbies
- 2) Caregivers and youth match youth interests and hobbies with work, education, and community options
- 3) Caregivers and youth review the vision board created by youth
- 4) Caregivers and youth create an action plan
- 5) OTDS follows up and modifies action plan with caregivers and youth
- 6) OTDS follows up and reviews action plan with caregivers and youth

Theoretical Framework:

- Model of Human Occupation (MOHO)

PROGRAM OUTCOMES

Participants: Participants at The Adult Transition Program services youth with intellectual and developmental disabilities from 18 to 22 years old. For the project, participants were all female, 21 to 22 years of age, with mild intellectual and developmental disabilities. Caregivers of youth were mothers, fathers, and adult sisters. All participants were able to speak and read English and had access to an electronic device to access program virtually.

Strengths: Overall receptiveness of site staff, caregivers, and youth to the program.

Limitations: Low number of participants, no male youth, no youth with moderate or severe intellectual and developmental disabilities, 3 of 5 caregiver and youth pairs completed the 6-week program, COVID-19 protocols impacted attendance.

Participants and Responses: 5 pairs identified, 4 pairs interested, and 3 total pairs completed the entire 6-week program

Table 8 Service delivery breakdown for each weekly session

Week	Service delivery
1	3 youths in-person, 1 youth virtual
2	Session 1: 3 youths in-person, 1 youth virtual Session 2: 1 pair in-person, 3 pairs virtual
3	1 pair in-person, 2 pairs virtual
4	3 pairs virtual
5	3 pairs virtual
6	3 pairs virtual

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Table 7 Overall evaluation response

Question	Caregiver Answer	Youth Answer
2. On a scale from 1-10, how meaningful and productive was the caregiver-youth program? 1 being not meaningful and productive and 10 being very meaningful and productive	100% - 10	100% - 10
3. What was most beneficial about the session?	37.5% - Content 43.75% - Interaction 12.5% - Service delivery	40% - Content 40% - Interaction 20% - Service delivery
4. What was unnecessary about the session?	100% - none	100% - none
5. How was the length of the session?	6.25% - too short, 93.75% - just right	5% - too short, 95% - just right

CONCLUSION and IMPLICATIONS FOR OT

An occupation-based program provided to caregivers and their youth transitioning to adulthood increases caregiver expectations and enhances the caregiver and youth relationship.

Improve occupational therapy's role in supporting caregivers of youth by working with caregiver and youth pairs. A future direction includes developing a program for caregivers and youth with moderate to severe intellectual and developmental disabilities.