

Postschool employment experiences of young adults with Down syndrome and their caregivers

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My Perspective

- Sibling
- Advocate
- Researcher
- *Areas of focus:* Down syndrome, socio-emotional development, language and communication
- *Research Aim:* Support social communication in individuals with intellectual disability such as Down syndrome in ways that support their learning and independence
 - *Goal: Successful transition to adulthood*

Your Perspectives

- Educator or other school-based professional
- Transition specialist
- Administrator
- Vocational rehabilitation
- Other state agency
- Self-advocate (person with a disability)
- Caregiver or sibling of a person with a disability
- Researcher or student
- Other



The Situation: Teacher Education & Transition Planning

- Only **35%** of special education licensure programs require a dedicated course in transition or transition planning (Williams-Diehm et al., 2018)
- Many educators graduate with **little-to-no transition education** embedded in their other special education coursework (Anderson et al., 2003; Morningstar et al., 2018)
- Many transition plans **do not meet the required mandates of IDEA**, particularly in the use of age-appropriate transition assessments (Prince et al., 2014)
- This tells us there's room to grow and improve

Postschool Transitioning in Down Syndrome

- Most common genetic cause of intellectual disability
- People with Down syndrome have a spectrum of abilities and support needs, many with extensive support needs
- Most transition research is reported across different types of disability and levels of support needs, making it difficult to apply

Postschool Transitioning in Down Syndrome

Little research on postschool transition outcomes in this population, virtually none in the first few years after high school




Many adults with Down syndrome say they want more independence, including community-based employment
(Foley et al., 2014; Ijezie et al., 2023; Jevne et al., 2021)



By better understanding outcomes, we can identify needs and supports to improve transition planning & services

Objectives



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graph LR; A[Share our research on employment outcomes in young adults with Down syndrome] --> B[Discuss findings and implications for practice]; B --> C[Provide recommendations and resources for practitioners];
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Share our research on employment outcomes in young adults with Down syndrome

Discuss findings and implications for practice

Provide recommendations and resources for practitioners

Research Study Aims

1

Report the employment rates of young adults with Down syndrome in the U.S. within 5 years of exiting high school

2

For those who were employed:
Characterize the nature of their employment

3

For all (employed & unemployed):
Explore their satisfaction with employment experiences

Survey Participants: Primary Caregivers

- $n = 101$
- Adult child with Down syndrome
- Exited high school in last 5 years
- Majority mothers (91%)
- Majority white (93%)
- Living in 24 states, including IL

Educational Background	%
High school/GED	8%
Some associate's	20%
Associate's or technical degree	8%
Bachelor's degree	31%
Graduate/professional degree	34%

Young Adults with Down Syndrome

- $n = 101$
- 18-26 years (Mean = 22.51, SD = 2.05)
- 46% female; 54% male
- Majority White (92%)

Recency of High School Exit	
< 6 months	18%
6-11 months	11%
1-2 years	27%
3-4 years	22%
4-5 years	23%

Online Survey Design

Background Information
Demographics
Educational environment

Outcome Variables
Community-based living (National Longitudinal Transition Study-2)
Community engagement (Community Integration Scale; Heller & Factor, 1991)
Employment (Vocational Index; Taylor & Seltzer, 2012)

Correlates
Daily living skills (Waisman Activities of Daily Living; Maenner et al., 2013)
Challenging behaviors (Scales of Independent Behavior-Revised; Bruininks et al., 1996)
Parent involvement in transition (Kraemer & Blacher, 2001)
Parental perceived support (Multidimensional Scale of Perceived Social Support; Zimet et al., 1988)

Open-Ended Survey Questions

For those who were employed, we asked caregivers:

What kind of paid work do they do?

Briefly describe what your child does and where they they work.

How did they find their paid job?



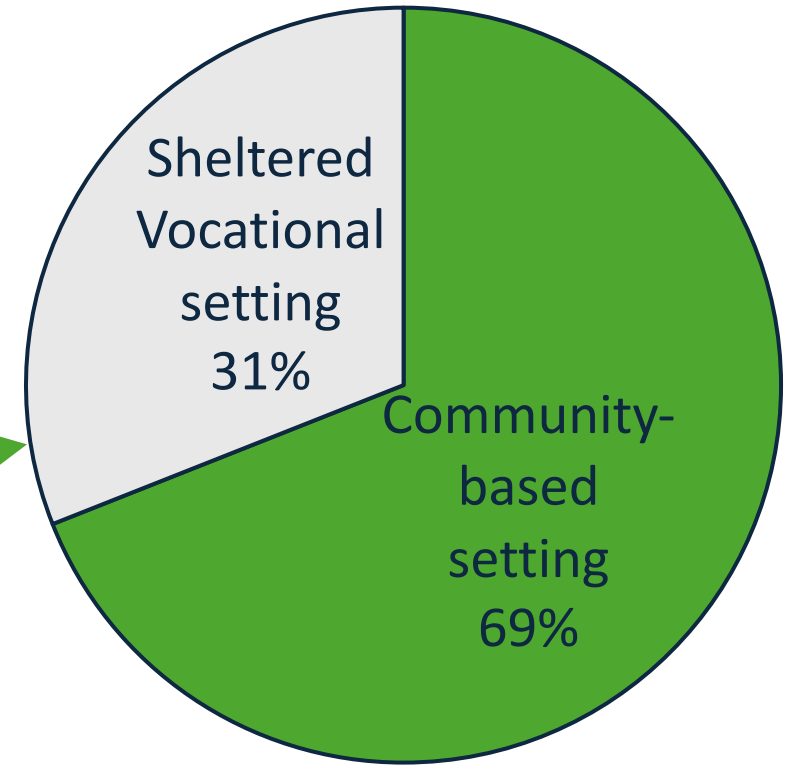
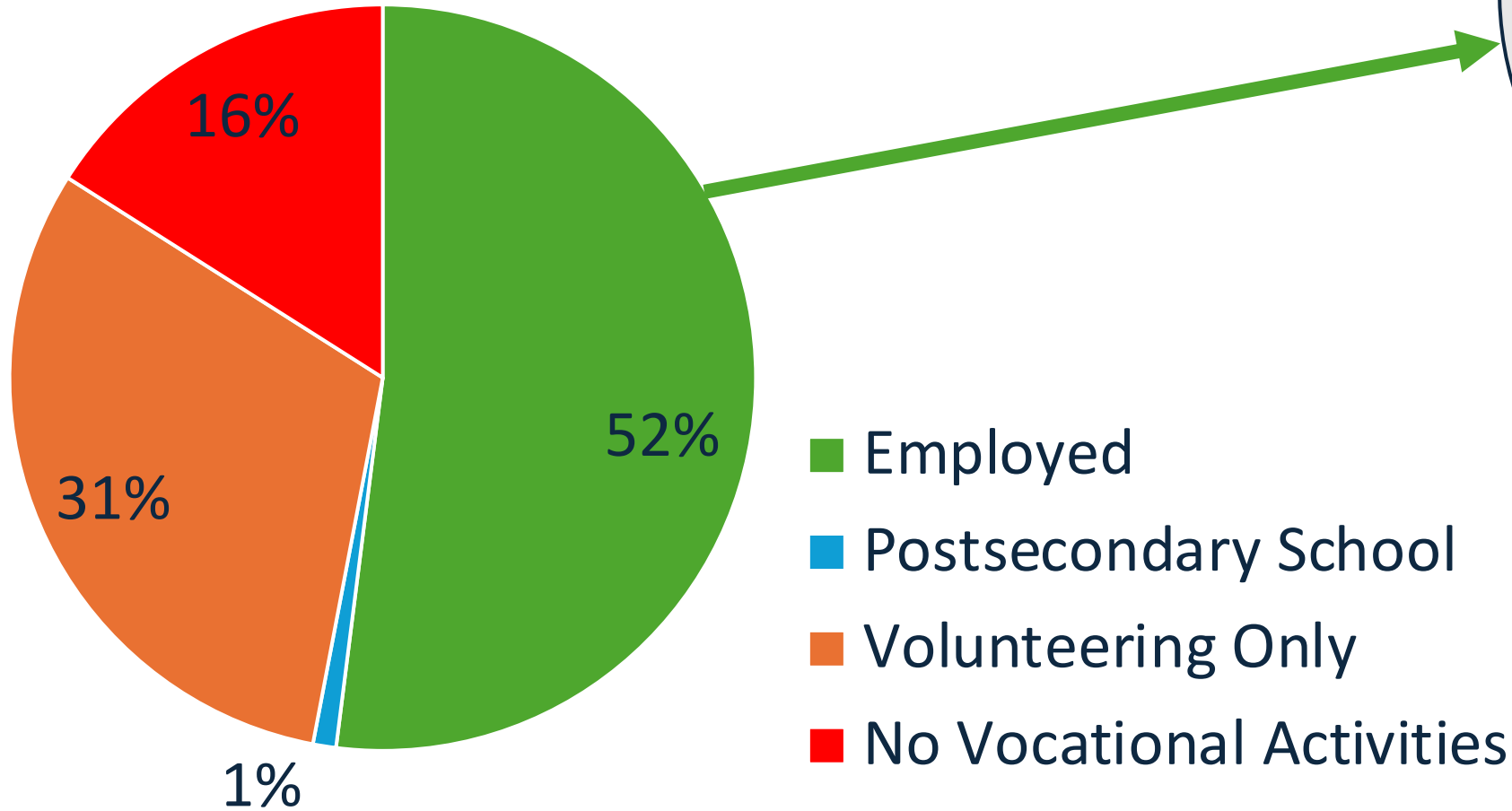
Research Aim 1

Report the employment rates of young adults with Down syndrome in the U.S. within 5 years of exiting high school

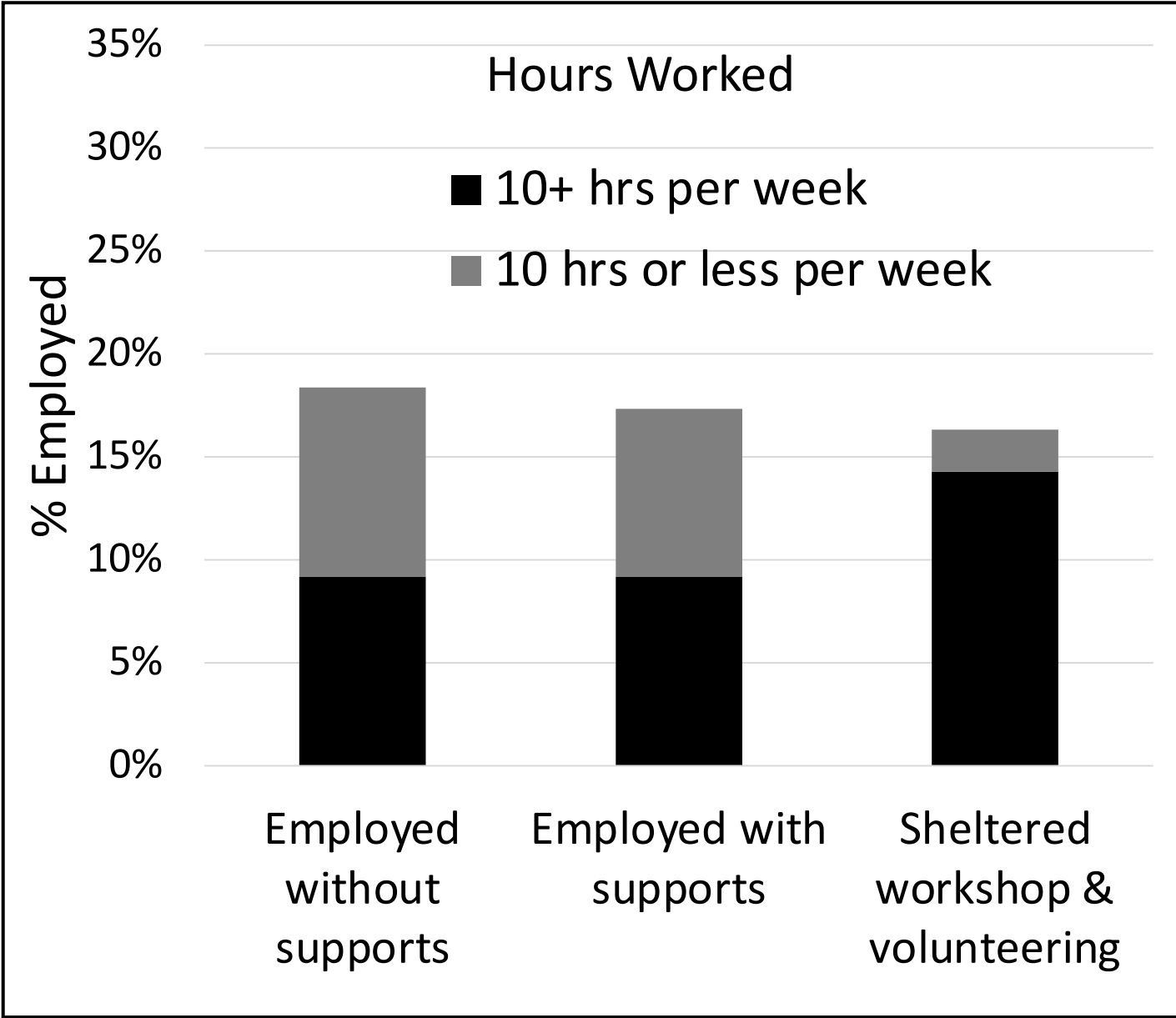


Post-High School Transition Outcomes for Young Adults With Down Syndrome

Susan J. Loveall, Marie Moore Channell, Meghan M. Burke, and Derek B. Rodgers





- Employed
- Postsecondary School
- Volunteering Only
- No Vocational Activities





Research Aim 2

Characterize the nature of employment for
those who were currently employed



Exploring Caregiver Perceptions of Post-High School Employment Experiences Among Young Adults With Down Syndrome

Marie Moore Channell ; Susan J. Loveall; Meghan M. Burke

Intellect Dev Disabil (2023) 61 (2): 158–171.

Job Task Categories	Frequency
Cleaning (e.g., laundry; dishes; busing tables)	18
Food prep	7
Ushering & greeting (e.g., host; ticket-taker)	5
Customer service (including delivery)	6
Clerical (e.g., organizing; stuffing envelopes)	4
Stocking	4
Assembly (e.g., piecework)	3
Film and media work	1
Outreach for local Down syndrome org.	1
Preschool aide	1

Employer Types	Frequency
Restaurant	7
Store	4
Disability org.	3
University	3
Church	2
Grocery store	2
Hotel	2
Movie theater	2
Dog daycare	1
Electronics corp.	1
Golf course	1
Gym	1
Hospital	1
Nursing home	1
Preschool	1
Private clinic	1
Production company	1
Rec center	1

How They Found Work (Channell et al., 2023)

Source	Frequency
Parent/Caregiver	7
Vocational program or job training service	6
Another relative or family friend	5
Rehabilitation agency counselor	4
Employment agency	3
School counselor	3
Teacher	3
Independently	3
Recruited by employer	2
Job fair	1

“The manager of one of the Home Depot stores came to our local Buddy Walk for Down syndrome where Dylan was telling knock-knock jokes. After the Buddy Walk he told the manager of a different Home Depot store that Dylan was an awesome young man and she should hire him. Then he found a way to contact someone in our group to get the word to Dylan that he should apply at that Home Depot store. Dylan called and made an appointment with the manager and she hired him on the spot.”



Research Aim 3

Explore satisfaction with employment experiences
for all (both employed and unemployed)



Satisfaction Coding & Theme Identification

Caregiver satisfaction with their young adult's current employment situation

Caregiver *perceptions* of their young adult's satisfaction with their current employment situation

Caregiver Satisfaction Themes (Channell et al., 2023)

Young Adults' Enjoyment and Fulfillment Through Work (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Socialization Opportunities Through Work (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Job Fit for the Young Adults (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Extent of Job Supports for the Young Adults (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Young Adults' Learning and Gaining Independence Through Work Was Related to Caregiver Satisfaction

Limited Employment Opportunities Were Related to Caregiver Dissatisfaction

Lack of Community-Based Employment Was Related to Caregiver Dissatisfaction

Lack of Paid Work Related to Caregiver Dissatisfaction

Caregiver Satisfaction Themes (Channell et al., 2023)

- Many caregivers reported a mixture of satisfaction and dissatisfaction

EXAMPLE:

Allison, who helped her son find a job cleaning at a church in Illinois, wrote:

"[I] sometimes wonder if he should get a job with more hours and more diverse work tasks but he does seem to like his jobs even though they are the traditional types of jobs people with disabilities have."

EXAMPLE:

Sarah wrote about her 22-year-old son who primarily communicated through assistive technology, was unemployed, attended a day program, and volunteered at a community garden and local library in Illinois. She reported,

"I wish he could have a small job a few hours a week for the experience but we need help in obtaining that. Otherwise, what he has now is working super!!"

Young Adults' Enjoyment and Fulfillment Through Work (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Satisfaction:

- Their enjoyment
- They like sharing their passion with others
- Pursuing their dream

Sheila, whose 24-year-old son worked at a golf course in Missouri, reported *"I am satisfied because he is happy and loves his job."*

Dissatisfaction:

- Unhappy
- Unfulfilled

Marilyn, whose son found janitorial work at a gym through an employment agency in Washington, wrote *"He's capable of doing much more. He's a social person who likes to help people."*

Sandy, whose 20-year-old daughter was unemployed and attending a day program in North Carolina while volunteering as a preschool aide, wrote *"she has many skills that would allow her to contribute to the betterment of the community."*

Socialization Opportunities Through Work (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Satisfaction: _____ →

- Interacting with peers
- Making friends
- Enjoying interactions with customers
- Interacting well with their boss and/or job coach

Anna reported that her 19-year-old daughter *“loves her co-workers”* at a retail clothing store in Colorado where she worked 10-15 hours a week

Dissatisfaction: _____ →

- Wanting their young adult to have more socialization opportunities through work

Dianne’s 25-year-old son with co-occurring autism spectrum disorder, attention-deficit hyperactivity disorder, and epilepsy volunteered at a thrift store in Missouri and was unemployed. She reported, *“I think being out of the house at least a few days a week in the right program could help him socially and behaviorally.”*

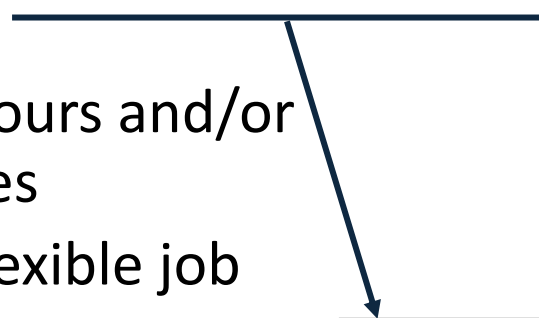
Job Fit for the Young Adults (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Satisfaction:

- Flexible hours
- Location close to home
- Good employer/setting

Dissatisfaction:

- Want more hours and/or responsibilities
- Want more flexible job
- Want job closer to home
- Toxic work environment (e.g., bullying)



Yvonne, whose 19-year-old daughter worked 4-8 hours a week as a hotel laundry attendant, reported that she *“would like to see expanded hours and responsibilities in her paid job.”*

Danny, who helped his 19-year-old daughter find work in a hotel laundry department in Illinois, wrote that the location *“is not conducive to using mass transportation, so she still relies on parents for transportation.”*

Extent of Job Supports for the Young Adults (or Lack Thereof) Impacted Caregiver (Dis)satisfaction

Satisfaction:

- Natural supports are helpful

Dissatisfaction:

- Employed, but want natural supports (vs. job coach)
- Unemployed, inadequate supports is a barrier to employment

Linda, whose 22-year-old daughter found jobs at a restaurant and a preschool through a post-school vocational program in Texas, wrote *“The preschool...wanted to train her themselves. That is a goal we strive for, natural supports!”*

Alegha reported that her son living in Arizona with co-occurring autism spectrum disorder, attention-deficit hyperactivity disorder, and low vision had no vocational activities (paid or volunteer). Alegha reported dissatisfaction with her son’s unemployment because *“he has not received any vocational skills training”* and that *“[Vocational] Rehab will deem him as 'unemployable.'”*

Themes Related Only to Caregiver **Dissatisfaction**

- Limited Employment Opportunities
- Lack of Community-Based Employment
- Lack of Paid Work

Penny reported that her daughter completed high school with a certificate 3-4 years prior, was unemployed, and volunteered at an adult day program in California. Penny wrote *"It just is not the best placement for her but there are so few choices with openings in our area. Most programs have wait lists for over a year."*

Morgan, a nonrelative caregiver to a 22-year-old woman working 15-20 hours per week doing assembly/piece work at a sheltered workshop in Illinois, wrote *"being in a small town there are very little options for employment for those needing assistance."*

Theme Related Only to Caregiver **Satisfaction**

- **Young Adults' Learning and Gaining Independence Through Work was Related to Caregiver Satisfaction**

Caregiver Perceptions of Young Adult Satisfaction Themes (Channell et al., 2023)

Finding Fulfillment Through Work Was Related to Perceptions of Young Adults' Satisfaction

Socialization Opportunities Were Related to Perceptions of Young Adults' Satisfaction

Job Fit (or Lack Thereof) Impacted Perceptions of Young Adults' (Dis)satisfaction

Learning New Skills and Gaining Independence Through Work Was Related to Perceptions of Young Adults' Satisfaction

Paid Work (or Lack Thereof) Impacted Perceptions of Young Adults' (Dis)satisfaction

Caregivers Unsure of Their Young Adults' (Dis)satisfaction

- Similar themes, yet nuanced differences in reasons for (dis)satisfaction

Job Fit (or Lack Thereof) Impacted Perceptions of Young Adults' (Dis)satisfaction

Satisfaction:

- Like the routine, environment, schedule, and/or tasks

Morgan, a caregiver to a 22-year-old woman who worked in a sheltered workshop in Illinois, reported that the young adult *“states [she] enjoys working at workshop and being with friends.”*

Dissatisfaction:

- Want more hours
- Want more or different responsibilities

Madison, whose 25-year-old son worked in a sheltered workshop in Illinois doing occasional piecework, reported *“He only goes a few days and not much to do there.”*

Anna, whose 19-year-old daughter worked 10-15 hours a week at a clothing store in Colorado, wrote *“She loves it, but also wants to do more with her life, for example one day become a chef. She is also a competitive dancer and would love to get paid to dance.”*

Objectives

Share our research on
employment outcomes in
young adults with Down
syndrome

Discuss findings
and implications
for practice

Provide
recommendations
and resources for
practitioners

Summary of Findings

1. Within 5 years of leaving high school, half of the young adults with Down syndrome were employed

- Some in community settings, others in sheltered workshops

2. Most were employed in stereotypical, entry-level positions

- E.g., Cleaning tasks, working at restaurants and stores

3. High variability in how they found employment

- Formal (e.g., vocational rehab) & informal (e.g., caregiver assistance)

Summary of Findings

4. Natural supports (vs. formal services) were key to obtaining and maintaining satisfactory employment

- Formal supports were not enough
- Natural supports also matter

Summary of Findings

5. Mixture of satisfaction and dissatisfaction with employment situation

- Job Fit: Finding the **right job** matters
- Learning new skills & gaining independence: Adaptive (daily living) skills are especially important for positive outcomes
 - Research shows a **bidirectional** relationship between employment and adaptive skills (Foley et al., 2013; Loveall et al., 2022; Tomaszewski et al., 2018)
- Social benefits mentioned across employment settings, but **fulfillment** only mentioned in the context of **community-based settings**

Limitations & Next Steps for Research

Only the caregiver's perspective

- Insight into their experience as they help their young adult navigate employment
- Missing direct perspectives from the young adults

Participants were majority white mothers with college degrees

- Unknown how our findings apply to others
- Even in a relatively well-resourced sample, many barriers to satisfactory employment

Next steps:

- Ask young adults with Down syndrome from diverse backgrounds about their experiences, barriers, and support needs
- Develop programming to meet those needs

Implications for Practice

1. More training opportunities for educators
2. Better transition planning
3. More opportunities for employment
4. More and better formal supports

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and implications
for practice

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recommendations
and resources for
practitioners

Implications for Practice

1. More training opportunities for educators
2. **Better transition planning**
 - Starts with assessment
 - Concrete considerations for carry-over after graduation
 - Supporting the development of relevant adaptive and academic skills
3. More opportunities for employment
4. More and better formal supports

Recommendations for Practice (Deardorff, 2021; Prince et al., 2014; Williams-Diehm & Sinclair, 2022)

➤ Use transition assessments to guide the transition planning process



Transition Services

Annual Goals for Transition

Transition Skill Assessments

Student Selected Postsecondary Goals

Interest Inventories & Exploration Tools

- Administer transition assessments annually
- Use a variety of assessments (2+)
- Use formal AND informal assessments
- Get input from >1 stakeholder
- Assess all transition areas
 - Postsecondary education/training
 - Employment
 - Independent living
 - (Self-determination)

Recommendations for Practice (Williams-Diehm & Sinclair, 2022)

General Transition Assessments – Formal

- Transition Assessment & Goal Generator (TAGG-HS, TAGG-A)
 - Professional, Parent, Student versions
- Transition Planning Inventory – 3rd Ed (TPI-3)
 - Multiple stakeholders; Validated for students with extensive support needs
- Support Intensity Scale (SIS)

General Transition Assessments – Informal

- Employability/Life Skills Assessment (ELSA)
 - Family, Transition team versions

Recommendations for Practice (Williams-Diehm & Sinclair, 2022)

Employment Assessments – Formal

- [My Next Move \(O*Net Interest Provider\)](#)
- Career exploration videos to learn options
- Provide tasks associated to the job chosen
- [Reading Free Vocational Interest Inventory](#)

Employment Assessments – Informal

- [Photo Career Quiz](#)
- Autonomy
- Open to interpretation, sparks discussion

Recommendations for Practice (Williams-Diehm & Sinclair, 2022)

Self-Determination Assessments – Formal (All FREE!)

- [AIR Self-Determination Scale](#)
 - Measures “capacity” (student knowledge, skills, & perceptions that enable self-determination) + “opportunities” (chances to use their knowledge & skills in different environments, including home)
- [ARC Self-Determination Scale](#)
 - More straightforward for students, hard to score (TIP: Help line is helpful!)
 - Report uses results to provide goal planning guide, including teaching activities & strategies with examples
- [Self-Determination Inventory](#)
 - TIP: Take screenshots of results, won’t automatically save (one-time use)

Recommendations for Practice (Williams-Diehm & Sinclair, 2022)

Independent Living Assessments – Formal

- [Adaptive Behavior Evaluation Scale \(ABES\)](#)
- [Transition Behavior Scale](#)

PRO TIP: Save time!
If the student already
has an adaptive
behavior assessment in
the last year, use that!

Independent Living Assessments – Informal

- [Informal Assessments for Transition Planning Guide](#)
- [Life Skills Inventory](#)

Recommendations for Practice (Williams-Diehm & Sinclair, 2022)

- **There is no perfect assessment tool.**
- The key is to choose the **right fit** for the **individual student**, keeping in mind the guiding principles:
 - Administer transition assessments annually
 - Use a variety of assessments (2+)
 - Use formal AND informal assessments
 - Get input from >1 stakeholder
 - Assess all transition areas

Implications for Practice

1. More training opportunities for educators
2. Better transition planning
3. **More opportunities for employment**
 - Barriers: limited ways to find employment, long wait lists for services
 - Start early!
4. More and better formal supports

Implications for Practice

1. More training opportunities for educators
2. Better transition planning
3. More opportunities for employment
4. **More and better formal supports**
 - Our data show informal, natural supports were key to obtaining and being satisfied with employment (see also Sanderson et al., 2017)
 - Transportation
 - [National Technical Assistance Center on Transition](#)

Thank You!

- Participating families
- Dr. Susan Loveall
- Dr. Meghan Burke
- Annalise Valle, Melissa Pietrowicz, Kelsey Libert, Nadia Hernandez

Questions?

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