Supporting Families in Connecting Their Adult Family Members with IDD to Employment: A Mixed-Methods Intervention Development Project

Ben Schwartzman, PhD
Vanderbilt University
My Background

UCSB KOEGEL AUTISM CENTER

SEMEL INSTITUTE UCLA

Tailored Day Service

FOOTHILL COLLEGE
Tools for Transition and Work

VANDERBILT UNIVERSITY
My Sibling

- Joey is 37
- He lives in an apartment with a friend from UCLA Pathway Program
- He drives
- Has had an extensive work history
Joey’s Trajectory After High School

- Recycling Center
- UCLA Extension Pathway
- Rosies Foundation
- Dishwasher at Home for Elderly
- Paid internship ended in early 2023
- ting Crazy Fast Fiber Internet®
What supports do families need as they navigate they support their family members with IDD in connecting to paid employment?
AGENDA

Project Overview

Phase I – Qualitative Study

Phase II – Pilot Study

Phase III – Randomized Controlled Trial

Next Steps
Project Overview

Tennessee's employment landscape and background on our project
The Importance of Employment

How important is finding or keeping a job?

Surveyed over 3,000 Tennesseans

Individuals with Disabilities 88%

Parents 86%

Tennessee Disability Services Study (2021)
Finding Employment Support

Do you know who could help you or your family?

- Surveyed over 3,000 Tennesseans
- Individuals with Disabilities: 50%
- Parents: 54%

Tennessee Disability Services Study (2021)
74% of Tennesseans are employed

35% of Tennesseans with disabilities are employed

39% employment gap

Community Inclusion (2020)
Changing the Landscape

VCU RRTC IDD
To increase employment outcomes for adults with intellectual and developmental disabilities

TN Employment Pathways Project
Supporting families in connecting their family members to paid employment through access to needed information and mentorship
Our Development Process

**Phase I**
- Interview 60 parents about the pathways to work

**Phase II**
- Develop supports and materials
  - Pilot intervention

**Phase III**
- Refine materials
- Evaluate within rigorous study (50+ families)

**Phase IV**
- Package materials, stories, and findings
Phase I - Qualitative Study

Focus groups and interviews with 60 families
“The more I’ve thought about it and talked to other people, a lot of the reasons we would want any family member to have employment apply to our son. Sense of self, sense of identity, sense of accomplishment.”

- Father of a 22-year-old son with autism
Barriers to Employment

“I’m a mama bear. And so a lot of what I’ve learned is trial and error, and hunting and pecking, and emailing. And I have spent unbelievable amount of hours, and I still don’t have all the answers.”

- Mother of 21-year-old son with autism
Common Barriers to Employment

- Individual
- Family
- School
- Disability Service System
- Workplace
- Community
Facilitators to Employment

- Family Involvement
- Assistance to Families
- Resources for Families
- Benefits Counseling
- Access to Services
- Connecting with Other Families

Schwartzman et al., (in press)
*Rehabilitation Counseling Bulletin*
Parent Perspectives on Meaningful Work

“More Than a Paycheck”: Parent Perspectives on Meaningful Work for Individuals With Intellectual and Developmental Disabilities

Erik W. Carter, Emily R. Lanchak, Laura Guest, Elise D. McMillan, Julie Lounds Taylor, and Hannah Rowley

Carter et al., 2023 “More Than a Paycheck” in Journal of Intellectual and Developmental Disabilities
Barriers to Employment

Family Perspectives on the Complexities of Pursuing Integrated Employment for Adults With Intellectual and Developmental Disabilities

Erik W. Carter, Emily R. Lanchak, Laura Guest, Elise D. McMillan, Julie Lounds Taylor, Laurie P. Fleming, and Anh Dao

Carter et al., 2023 in American Journal on Intellectual and Developmental Disabilities
Project Briefs: Insights from Families

**Project Brief 1**

**The Voice of Families: Exploring Perspectives on the Pathways to Integrated Employment**

"I’d be honored, sometimes it feels like a blur. I keep trying to get a toehold with housing and finding a place to live. My son last year, he’s 15, he’s autistic, and he’s working towards living more independently. Now he’s in a shelter with a counselor, they’re teaching him how to budget, how to save money, and how to live on his own. It’s been a big step, it’s been a big challenge, but he’s doing well and he’s improving.

"- Mother of an 18-year-old son with autism

**Meaningful Work for Individuals with IDD: Insights from Families**

"Finding a job is a daunting and stressful process. It’s not just about finding a job, it’s about finding a job that is meaningful, that provides a sense of purpose and fulfillment. It’s about finding a job that allows for personal growth and development. It’s not just about making a living, it’s about making a difference. It’s about finding a job that is worth doing for the people who need it.

"- Father of a 25-year-old son with Down Syndrome

**Project Brief 3**

**Barriers to Employment for Individuals with IDD: Insights from Families**

"The actual skill of doing the job is never going to be the problem. It’s navigating all of the things that come with the job, like dealing with coworkers, or customers, or clients. It’s dealing with the stress, the anxiety, the uncertainty. It’s dealing with the fact that you’re on the job, you’re in a position of authority, and you’re responsible for other people. It’s dealing with the fact that you’re in a position of responsibility, and you’re responsible for other people. It’s dealing with the fact that you’re in a position of responsibility, and you’re responsible for other people.

"- Mother of a 22-year-old son with autism

**Project Brief 4**

**Supporting Integrated Employment Pursuits for Individuals with IDD: Insights from Families**

"I’m building his self-esteem, I’m building his confidence, I’m building his life skills. He’s learning to meet people, he’s learning to interact with people, he’s learning to work in a team. He’s learning to take on responsibility, he’s learning to be a part of a team. He’s learning to be a part of a community, he’s learning to be a part of a society.

"- Mother of a 16-year-old daughter with Down Syndrome

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Webinar: The Voices of Families

VCU-RRTC-IDD
VCU-RRTC on Employment of Persons with Intellectual and Developmental Disabilities

The Voice of Families: Pathways to Integrated Employment for Individuals with IDD

Vanderbilt University & Vanderbilt Kennedy Center for Excellence in Developmental Disabilities (UCEDD)
Phase II – Pilot Study

Four-family pilot of intervention
Pilot Study Support Package

Information Access

Family Support
Who can help me?

Vocational Rehabilitation – Once you have an open case with Vocational Rehabilitation, they have local organizations and career centers ready to help with skills discovery and growth. To learn more about what they offer, contact your local office. Click the link for a list of all state offices.

Teachers – Ask your job seeker’s teachers about skills they developed during school and/or work-based learning activities. Their teachers are a wealth of knowledge in this area. They may also know volunteer supervisors to contact and include as references.

FAQ

What if my job seeker’s interests don’t match their skill sets?

It is common for interests to not match skills... at least at first glance. The key is to take time and brainstorm with an open and creative mind. Use your support team (from section 1) to discuss ideas (friends, teachers, job coaches, etc.). Example: Sally was interested in drawing and mentioned it during her interview at a healthcare company. They hired her in Human Resources for her skill set of organization, but put her on side art projects for their magazine.

What if my job seeker would like to grow in a skill, that they have not yet mastered?

Motivation to grow in a skill is key! There are a lot of community resources and free online tools for growing in skills. Contact your local Vocational Rehabilitation office and share specific skills your job seeker is interested in learning to learn about local options. You can also learn Microsoft office skills for free online. We recommend looking for a company that has several positions your job seeker would be interested in pursuing long-term. Career growth is key and you want their supervisor to know their long-term goals early on, so that either their co-workers or a job coach can support their learning efforts.

Is it okay to ask a company to help train and grow a skill set?

Employers are only required to train employees in a reasonable timeframe. If your job seeker needs additional training or skill set development, we recommend asking the supervisor. First. If they don’t have time to adequately train grow a skill set, you can request job coaching from several agencies.

Section Features:

- Key employment-related information
- Person-centered planning activities
- Community and national resources
- Online resource links
- Support team members
- Frequently asked questions
Journeys of Families

Lanchak et al. (2023) *Complex Employment Journeys: Case Studies of Four Families of Adults with Intellectual Disability*
## Demographics

### Parent of Job Seeker

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Family Information</th>
<th>Community Type</th>
<th>Employment Experience</th>
</tr>
</thead>
</table>
| **Mother** 53 years old White | Married 3 children | Living in urban area | Areas of need:  
  • Developing support team  
  • Finding local businesses  
  • Identifying supports and accommodations |

### Mentor

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Family Information</th>
<th>Community Type</th>
<th>Employment Experience</th>
</tr>
</thead>
</table>
| **Mother** 56 years old Black | Married 2 children | Living in urban area | Mentor strengths:  
  • Knowledge of supports and service system  
  • Thinking creatively about employers and job types  
  • Problem solving |
## Dyad 2 Participants

<table>
<thead>
<tr>
<th>Demographics</th>
<th>Disability Category</th>
<th>Daily support needs</th>
<th>Employment Experience</th>
</tr>
</thead>
</table>
| **Job Seeker** | Male 21 years old White | Intellectual disability and Autism spectrum disorder | Some support | Interests:  
• Talking with others  
• Cars |
| **Employed Adult** | Male 25 years old Black | Autism spectrum disorder | A little support | Works at Advanced Auto Parts warehouse |
“The steps for employment for [my son] began when I first started speaking with my mentor. She shared her story and the steps she has taken including pitfalls. We utilized information supplied with our Roadmap to Employment guide and it helped start us on the correct path.”

- Mother of 21-year-old seeking employment
Finding Employment

Job Title
Porter Assistant at car dealership

Responsibilities
Stock refreshment bar, wipe down tables, maintain showroom floor and stations

Favorite Part
Talking with customers and coworkers; personalized name tag
Role of the Mentor

“My mentor has been wonderful, and I know if I have a question, she will find the answer. She helps encourage me on next steps and keep organized. She is great to work with and I feel I've gained a friend.”

- Mother of 21-year-old seeking employment
Phase III – Randomized Controlled Trial

Expanded intervention through RCT with 58 families
RCT Support Package Updates

Information Access

- Added "Short Course" of 4 weekly Zoom classes at beginning of year
- Created “Employment Planning Tool”
- Updated Roadmap to Employment

Family Support

- Developed mentor matching criteria
- Check-ins with Vanderbilt every other month for one year
Short Course Topics

- Employment Options
- Person-Centered Approach
- Job Ideas
- Types of Supports
- Programs in TN
- Connecting with Employers
Employment Planning Tool

1. STRENGTHS AND INTERESTS
   a. What do you enjoy doing (at home or in the community) in your spare time?
   b. What are some of your favorite places that you like to visit?
   c. What special interests, passions, or hobbies do you have?
   d. What are you really good at? What do people compliment you on?
   e. What personality traits or personal qualities would a potential employer love to know about you?
   f. Who knows you best (Can you name 1-5 people)?

2. PREVIOUS WORK-RELATED EXPERIENCES
   a. Where have you worked or volunteered in the past? Did you have any work experiences during school?
   b. What job did you enjoy doing the most? What did you enjoy doing the least? Why?

- Strengths and interests
- Previous work experiences
- Employment goals
- Transportation
- Needs and supports
- Connections
- Next Steps
Participants – Eligibility

**Job Seekers**

- Family of *unemployed* adult with IDD
  - Autism or Intellectual Disability
  - 18 or older
- Live in Tennessee
- Willing to connect with Mentor family monthly for one year

**Mentors**

- Family of *employed* adult with IDD
  - Live in Tennessee
- Willing to connect with Job Seeker family monthly for one year
Participants – Recruitment

**Job Seekers**
- 159 completed interest forms
- 66 eligible families completed Short Course
- 58 were randomized: 29 intervention, 29 comparison

**Mentors**
- 43 completed interest forms
- 25 eligible Mentors participated
- 3 were rematched
- 1 mentored two Job Seekers
<table>
<thead>
<tr>
<th>Participants</th>
<th>Job Seekers</th>
<th>Mentors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Sex</strong></td>
<td>91% Female</td>
<td>92% Female</td>
</tr>
<tr>
<td><strong>Average Age</strong></td>
<td>54.25</td>
<td>57.72</td>
</tr>
<tr>
<td><strong>Race/Ethnicity</strong></td>
<td>74% White; 18% Black; 5% Hispanic/Latino; 2% Native American</td>
<td>84% White; 16% Black</td>
</tr>
<tr>
<td><strong>Family Member’s Disability</strong></td>
<td>35% ASD; 31% ASD+ID; 21% ID; 13% DS</td>
<td>40% ASD; 8% ASD+ID; 40% ID; 12% DS</td>
</tr>
<tr>
<td><strong>Family Member’s Sex</strong></td>
<td>35% Female</td>
<td>32% Female</td>
</tr>
<tr>
<td><strong>Family Member’s Average Age</strong></td>
<td>23.58</td>
<td>25.80</td>
</tr>
<tr>
<td><strong>Employment History</strong></td>
<td>43% Never Employed; 57% Previously Employed</td>
<td>100% Currently Employed</td>
</tr>
</tbody>
</table>
Mentor Matching Priorities

**Job Seeker Characteristics**
- Disability, age, level of support needs, gender

**Employment Knowledge**
- Starting point on Roadmap, previous employment, familiarity with employment supports

**Location**
- East, Middle, West TN
- Rural or Urban

**Service Status**
- Enrollment in similar employment support services
Procedure

Month 0
- Baseline Survey & Short Course
- Randomized

Month 1
- Mentor Orientation
- Meet with Mentor
- Vanderbilt Check-in

Month 2
- Meet with Mentor
- Meet with Mentor
- Vanderbilt Check-in

Month 3
- Meet with Mentor
- Meet with Mentor
- Vanderbilt Check-in

Month 4
- Meet with Mentor
- Meet with Mentor
- Vanderbilt Check-in

Month 5
- Meet with Mentor
- Meet with Mentor
- Vanderbilt Check-in
Procedure

Month 6
- Vanderbilt Check-in + Mentor Survey
- Meet with Mentor

Month 7
- Vanderbilt Check-in
- Meet with Mentor

Month 8
- Vanderbilt Check-in
- Meet with Mentor

Month 9
- Vanderbilt Check-in
- Meet with Mentor

Month 10
- Vanderbilt Check-in
- Meet with Mentor

Month 11
- Vanderbilt Check-in
- Meet with Mentor

Month 12
- Vanderbilt Check-in
- Meet with Mentor

End of Project Survey

Int.
- Meet with Mentor
- Meet with Mentor
- Meet with Mentor
- Meet with Mentor

Comp.
- Vanderbilt Check-in
- Vanderbilt Check-in
- Vanderbilt Check-in
- Vanderbilt Check-in
## Tracking Journeys – Preliminary Findings

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<thead>
<tr>
<th></th>
<th>Intervention</th>
<th>Comparison</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Completed Study</strong></td>
<td>5 out of 8 Employed</td>
<td>2 out of 6 Employed</td>
</tr>
<tr>
<td><strong>In Progress</strong></td>
<td>11 out of 21 Employed</td>
<td>7 out of 23 Employed</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td>55% (16/29)</td>
<td>31% (9/29)</td>
</tr>
</tbody>
</table>
Short Course Feedback

- **73%** strongly agree: Provided strategies that were easily useful.
- **77%** strongly agree: Information was relevant to their current needs.
- **82%** strongly agree: Would recommend the course to others.

"It empowered the parents to come alongside their adult child in seeking employment."

"There were way more resources than I knew about. It was very helpful to get feedback and ideas from others."

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73%

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77%

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82%
Hear From Participants
Benefits of Mentorship

“The mentorship component was extremely helpful. The connections have helped a great deal. My mentor was great at helping my son find social outlets. We will continue to work together post study!”

- Mother of 24-year-old seeking employment
Benefits of Mentorship

“It was a really wonderful experience. [My son] is so much happier and more settled/confident today than where he was a year ago. The project was a huge help and resource. I learned so much and applied so much.”

- Mother of 24-year-old seeking employment
Benefits of Mentorship

“Every stage of life with your child with special needs is a challenge. Always knowing that someone is organized and prepared to walk this path is important and makes the journey less daunting.”

- Parent mentor
“I like to think I brought not only employment help but led a new person to my son’s community of friends. I am thrilled that my mentee’s family was warmly welcomed to my city and state, as well as lifted up and brought into lifelong friendship with my family.”

- Parent mentor
Next Steps

Future directions of this work
Publications

Phase I
Carter et al., 2023 – “More than a paycheck”... *Published in IDDs*
Carter et al., 2023 – Family perspectives on the complexities of pursuing paid employment... *Published in AJIDD*
Schwartzman et al., 2023 – Family perspectives on promoting paid employment... *Published in Rehabilitation Counseling Bulletin*

Phase II
Lanchak et al., – Complex employment journeys: Case studies of four families... *Accepted in JVR*

Phase III
Coming Soon!
RCT Baseline Data – *In Preparation*
RCT Findings – *Collecting Data*
Future Directions – Scale-up!

- Expand to other states: CA & VA
- Refine mentorship structure
- Partner with community providers
- Explore peer mentorship
Acknowledgments

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VCU and our collaborators in the RRTC-IDD

Our devoted families and mentors!
Questions + Answers