Supporting Families in Connecting Their Adult Family Members with IDD to Employment:

A Mixed-Methods Intervention Development Project

Ben Schwartzman, PhD Vanderbilt University

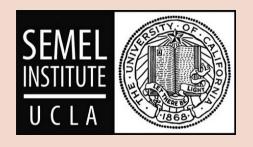






My Background







Tailored Day Service



Tools for Transition and Work



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













Dishwasher at Home for Elderly



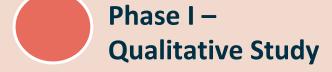
Paid internship ended in early 2023

What supports do families need as they navigate they support their family members with IDD in connecting to paid employment?

AGENDA











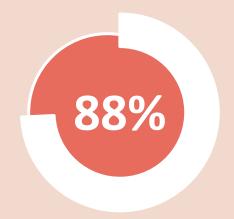


Tennessee's employment landscape and background on our project

The Importance of Employment



Surveyed over 3,000 Tennesseans



Individuals with Disabilities



Parents

Finding Employment Support



Surveyed over 3,000 Tennesseans



Individuals with Disabilities



Parents

Employment By the Numbers

74%

of Tennesseans are employed

35%

of Tennesseans with disabilities are employed

39%

employment gap

Changing the Landscape

VCU RRTC IDD

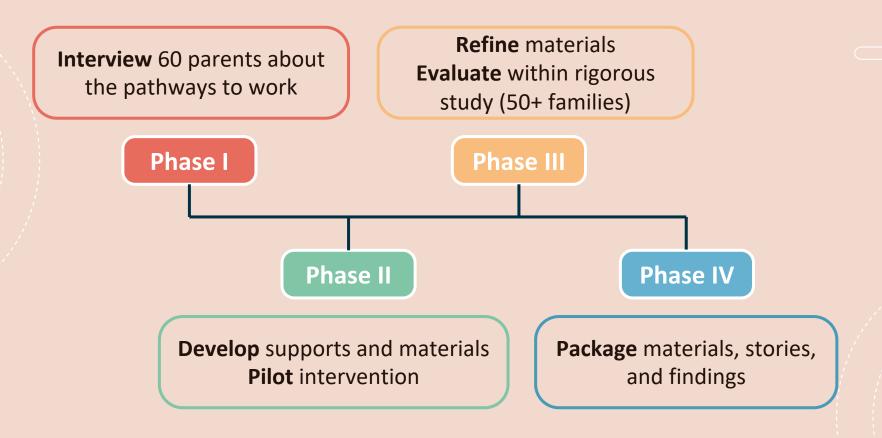
To increase employment outcomes for adults with intellectual and developmental disabilities

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 -Qualitative Study

Focus groups and interviews with 60 families

The Value of Work

"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



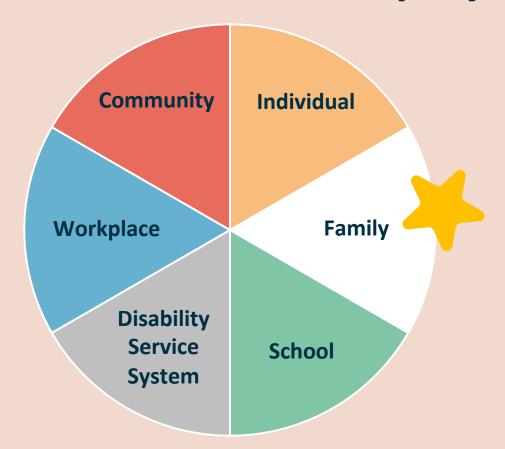
Barriers to Employment

"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



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



INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 2023, Vol. 61, No. 2, 145–157

©AAIDD

DOI: 10.1352/1934-9556-61.2.145

"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



AMERICAN JOURNAL ON INTELLECTUAL AND DEVELOPMENTAL DISABILITIES 2023, Vol. 128, No. 3, 219–236

©AAIDD DOI: 10.1352/1944-7558-128.3.219

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



The Voice of Families: Exploring Perspect on the Pathways to Integrated Employmer

"Ill be honest, sometimes it feels like a fulltime job trying to get in touch with resources and figuring out what we can do." ~Mother of 21-year-old daughter with IDD

This research study was supported through funding from the Rehabilitation Research and Training Center (RRTC) on Employment of Persons with Intellectual and Developmental Disabilities. The YCU-RRTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research (MDILIR) grant #998TRMM00001-00; NDILIRS or a Center within e Administration for Community Living (ACL), Department of ealth and Human Services (HHS). intellectual and developmental (IDD) want to participate fully in community. Although there are avenues for community inclusio good job may be among the mo A satisfying job provides opport develop new friendships, share meet the needs of others learn and assume valued roles. Morepaycheck provides resources fo personal needs and makes invo other community activities poss job can make a powerful differe of individuals with IDD!





Meaningful Work for Individuals with Insights from Families

> "I long for her to be getting more intellectual development and challenge at work, to be invited to push the envelope a little bit and see what more she can do."

~Sibling of 58-year-old sister with an intellectual disability

VANDERBILT

This research study was supported through funding from the Rehabilistion Research and Training Center (RICT) on Engloyment of Persons with Indelectual and Developmental Disabilities. The YCU-8RTC is funded by the National Institute on Disability, Independent Living, and Sehabilitation Research ONLINUR great PORTENDECODI CO, MIDILIAN B. Center within he Administration for Community Living (ACL), Department of leabh and Human Services (HHS). Elevating employment outcor viduals with intellectual and c disabilities (IDD) has been a lgoal of research, policy, and a ing access to the world for wi investment for people with d well as for their families, area and local communities. Indee cies and organizations now tr employment rates as a way o whether progress is being mi goal. For example, schools tri

rates one year after graduativocational rehabilitation traci successful employment outcomes, and state IDD agencies track the percentage of individuals involved in integrated employment







"The actual skill of doing the job is never going to be the problem. It is navigating all of the hidden agendas and water cooler talk. And the subtle cues of interacting with a boss that [he] might not quite understand."

~Mother of 22- year-old son with autism

This research study was supported through funding from the Rehabilitation Research and Training Center (RRTC) on Employment of Persons with Intellectual and Developmental Disabilities. The VCU-RRTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research NDLISR grant #96RTEM003301-003. NDLISR is a Center within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

A good job in the community can have powerful influence on the lives of adu with intellectual and developmental disabilities (IDD). Meaningful work domuch more than promote personal ar financial independence. It also brings of pride, creates social connections, a enhances well-being. Local employers hanafit from the diverse talents and d commitment individuals with IDD can to the workplace. Not surprisingly, cur policy and best practice all aim toward helping individuals with IDD access in employment that is aligned to their in

PROIECT BRIEF 3



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

"So they're building his skill.... I could tell the first day they did it. He came in all pumped up and happy and walking on his toes. It was good. And so just that little bit makes all the difference in the world."

-Mother of a 25-year-old male with autism

This research study was supported through furning from the Rehabilitation Research and Training Center (RRTC) on Employment of Persons with Intellectual and Developmental Disabilities. The YCU-8RTC is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research VOILURG grant ASPITEMBOOSTO, MIDLIRS for Enter within the Administration for Community Living (ACL), Department of Health and Human Services (HHS).

Individuals with intellectual and developmental disabilities (IDD) who are employed are making substantial contributions in the workplace-throughout Tennessee and across the country. They are sharing their gifts, talents, and passions in jobs that match their interests and strengths. Parents are encouraging these employment experiences and seeing first-hand the difference it makes in their family members with IDD. Schools and agencies are providing strong instruction and individualized supports that promote success on the job. And employers are benefitting substantially from their commitment to hiring a diverse workforce.

PROJECT BRIEF 4











Webinar: The Voices of Families





Phase II – Pilot Study

Four-family pilot of intervention

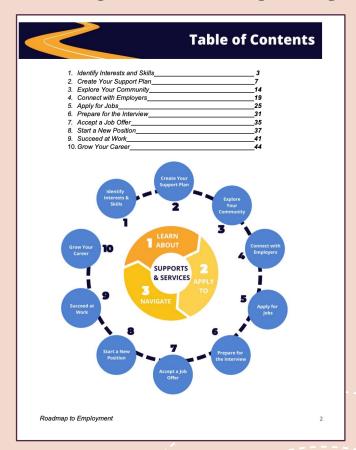
Pilot Study Support Package

Information Access

Family Support



Roadmap to Employment



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 health care 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.

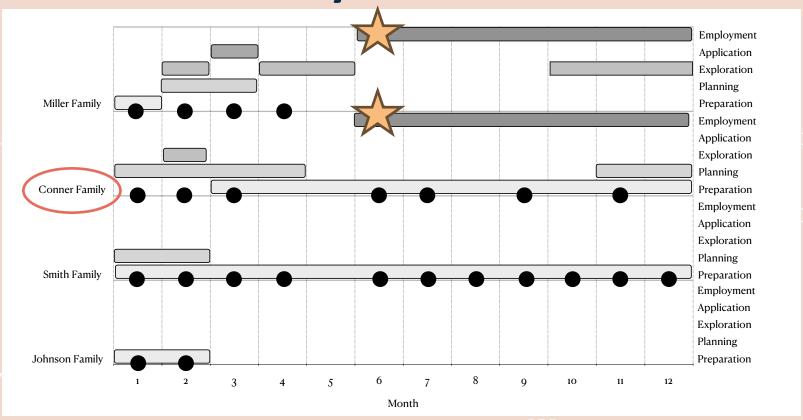
Is it okay to ask a company to help train and grow a skill set?

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

Dyad 2 Participants

	Demographics	Family Information	Community Type	Employment Experience
Parent of Job Seeker	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	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

	Demographics	Disability Category	Daily support needs	Employment Experience	
Job Seeker	Male 21 years old White	Intellectual disability and Autism spectrum disorder	Some support	Interests:Talking with othersCars	
Employed Adult	Male 25 years old Black	Autism spectrum disorder	A little support	Works at Advanced Auto Parts warehouse	

Getting Started

"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

Employment Planning Tool

Tennessee Employment Pathways Project - Vanderbilt University

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

Mentors

-Autism or Intellectual Disability
-18 or older

Live in Tennessee

Willing to connect with Mentor family monthly for one year

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 participated3 were rematched1 mentored two Job Seekers

Participants	Job Seekers	Mentors
Sex	91% Female	92% Female
Average Age	54.25	57.72
Race/Ethnicity	74% White; 18% Black; 5% Hispanic/Latino; 2% Native American	84% White; 16% Black
Family Member's Disability	35% ASD; 31% ASD+ID; 21% ID; 13% DS	40% ASD; 8% ASD+ID; 40% ID; 12% DS
Family Member's Sex	35% Female	32% Female
Family Member's Average Age	23.58	25.80
Employment History	43% Never Employed; 57% Previously Employed	100% Currently Employed

Mentor Matching Priorities

Job Seeker Characteristics

Disability, age, level of support needs, gender

Location

East, Middle, West TN Rural or Urban

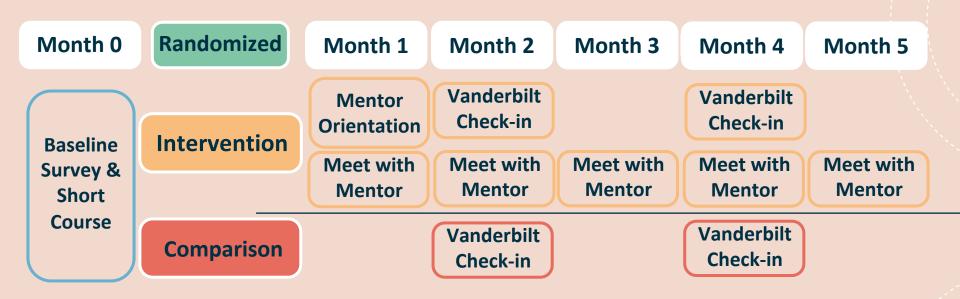
Employment Knowledge

Starting point on Roadmap, previous employment, familiarity with employment supports

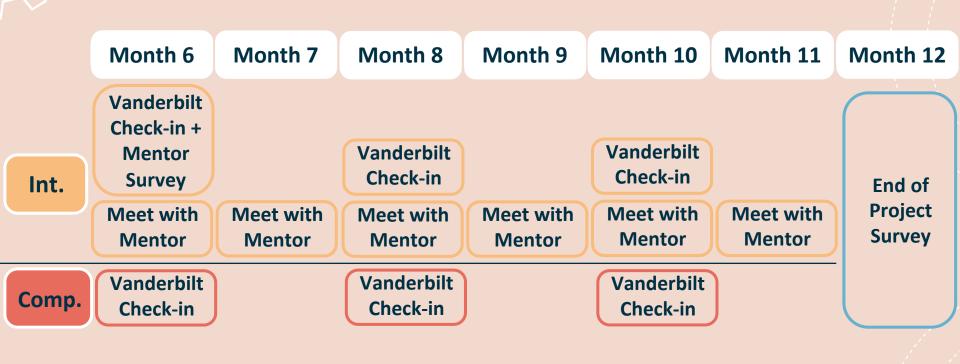
Service Status

Enrollment in similar employment support services

Procedure



Procedure



Tracking Journeys – Preliminary Findings

	Intervention	Comparison
Completed Study	5 out of 8 Employed	2 out of 6 Employed
In Progress	11 out of 21	7 out of 23
	Employed	Employed
Total	55% (16/29)	31% (9/29)

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."



Hear From Participants



"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



"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



"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





Publications



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



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

Coming Soon!

Phase III RCT Baseline Data – In Preparation

RCT Findings – *Collecting Data*

Future Directions – Scale-up!

Expand to other states: CA & VA

Partner with community providers

Refine mentorship structure

Explore peer mentorship

Acknowledgments

We would like to thank:



National Institute on Disability, Independent Living, and Rehabilitation Research (NIDILRR) Grant #90RTEM0003



VCU and our collaborators in the RRTC-IDD



Our devoted families and mentors!

Questions + Answers