Tools for Transition Success:

A Perspective from a Parent's Lived Experience

Presented by Leslea Lehoucq

Learning Objectives

By the end of this presentation you will understand:

- the experience of the current transition system for the family of a young person with "invisible disabilities."
- the parent perspective of the process of receiving disability services.
- lessons learned and recommendations.



Some terminology

Disability-related terminology for this presentation:

https://docs.google.com/document/d/12UQybku4YpdF5UQrVItwpCxKcOGXr 97w34V4rmYGm9s/edit?usp=sharing



Presentation Outline

- Introduction to my family and, in particular, my daughter, Catherine
- Challenges experienced because of invisible disabilities
- Our transition process
- Activity
- Lessons learned
- Tools and resources
- Discussion



Leslea Lehoucq

- Parent of children ages 16, 18, and 21
- Studied math and statistics
- Worked at Sandia National Labs for 5 years



- Worked with children as a reading tutor, classroom volunteer, Sunday school teacher, Director of Christian Formation, volunteer at Cuidando Los Niños, and most importantly, as a parent
- Entered world of supported employment as an investment in my daughter and her future as an independent person



NM CDD and PFE trainings

Since October 2022:

- WISE (Washington Initiative for Supported Employment) trainings about transition
- Training sessions offered by PFE trainers (Community Mapping and SSI Benefits)
- The 2023 Partners for Employment Reaching New Heights In Supported Employment Conference
- New Mexico Workforce Conference 2023
- The College of Employment Services course in fall 2023



Why I am here

- Hindsight is 20/20 (20/40?)
- Kids like my daughter, Catherine, may not qualify for some supports that could make a positive difference in their future
- Opportunities lost to not knowing about available helps
- Connections are SO IMPORTANT for getting information and help you need

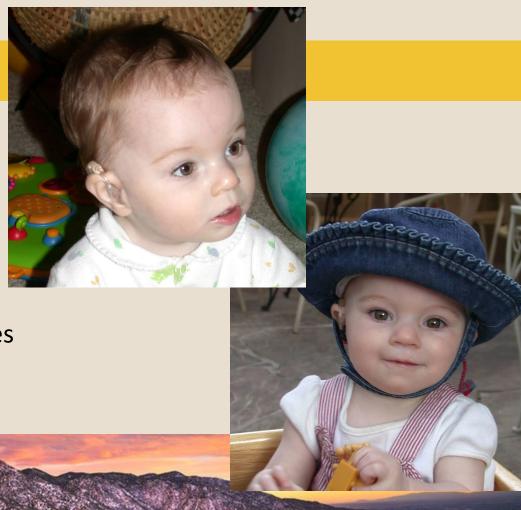


My call to action

- Help other families better understand processes and available resources
- Started a group called Challenge: Besting Disability
- Signed up for College of Employment Services fall 2023 cohort
- Applied for NMTA opportunity



- Motor delays
- Sensory processing issues
- Failure to thrive
- Hearing loss
- Hip dysplasia
- Specific learning disabilities
- ADHD
- POTS, gastroparesis



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- Physical Therapy
- Occupational Therapy
- Feeding Therapy
- Speech Therapy
- Vision Therapy
- Ear surgeries, hearing aids
- Appendix removal





- Loves to sing and dance
- Loves her family and friends
- Enjoys shopping and eating out
- Likes to engage with all sorts of people
- "Not a mean bone in her body



Catherine: Strengths

- Comfortable interacting with people of all ages
- Kind to and interested in others
- Beautiful voice
- Good cook
- Dependable employee
- Dreams big
- Bounces back from adversity
- Confident and values self
- Does not recognize potential limits



Catherine: Challenges

- Motor issues, cognitive processing issues
- Distractible
- Poor executive function
- Challenge with recognizing social cues and conversation nuances and expressing herself appropriately
- Sometimes over confident in her abilities and won't ask for help
- At work, she sometimes has not been monitored or coached to succeed; she did not disclose disability
- Chronic health issues
- Challenges with driving



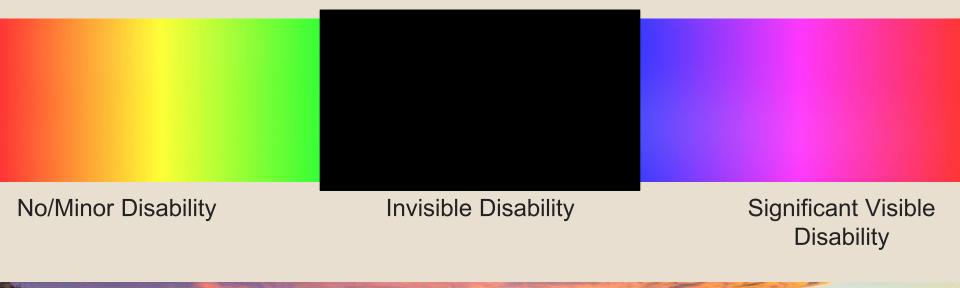
- Early Intervention/Child Find
- Inclusion classrooms, special ed pull-outs
- Social Communication program
- Cross-category special education

Catherine's High School

- Catherine received "cross-category" education services
 - ★ IEPs
 - * Specialized instruction in math, English, science classes
 - Some "integrated" classes: mix of regular ed and special ed kids with an additional teacher or educational assistant
 - * Job Mentorship Program (JMP)
 - ★ Transition Fair
- College is emphasized from freshman year
- Intensive Global Support Program



The Spectrum of Disability





The Spectrum of Disability

No/Minor Disability

Invisible Disability AKA The Pit of Despair

Significant Visible Disability

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Common Issues for People with Invisible Disabilities

Based on conversations with the *Challenge: Besting Disability* participants and transition specialists, we found challenges including

- Ability and desire to pass as not having functional limitations
- May be more vulnerable to being taken advantage of
- Difficulty clearly and appropriately expressing themselves



Common Issues for People with Invisible Disabilities

- Difficulty identifying depth of relationships
- Understanding verbal and non-verbal communication cues
- Limited practical understanding of their challenges



High School-Related Invisible Disability Challenges We Experienced

- Standard or modified pathway for graduation
- DD Waiver qualifications
- Project SEARCH qualifications
- May not have received information about learning or internship opportunities
- Skills for succeeding independently at a job, such as communication and work experience, do not seem to be emphasized as part of the curriculum



Think Like a Parent

- How is modified path eligibility determined?
- How is information distributed to students with invisible disabilities/their families as well as their ISG peers?
- How are kids with invisible disabilities receiving Pre-ETS services?



Think Like a Parent: High School

- How can kids with invisible disabilities receive the communication and self-advocacy skills for future independence?
- How can high school kids with invisible disabilities receive help in their first job(s)?
 - * Mentoring?
 - * Disclosing disability?
 - * Seeking accommodations?



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Lessons Learned & Tools and Resources: Up Through High School

Recommendations	Tools and Resources
Special Ed "PTAs"	Families within a school; school and agency presentations; videos
Transition planning separated from IEP	DVR, Workforce Connection, transition specialist
Consider graduation pathways	Speak to school personnel and experienced families about pros and cons of pathways
Start the ball rolling with DVR for families	Transition specialist, DVR rep work through referral with families, answer questions.
Explore post-graduate options and skill-building opportunities.	JMP, Career fairs, volunteer opportunities, social communication groups, work skills training, housing



Catherine's ambitions and work experience

- Wanted to be a nurse
- Worked in food service, retail
- Studied at CNM to be a Certified Nursing Assistant
- Worked in a nursing home as an activities assistant
- Currently studying Early Childhood Education at CNM and working at a daycare center



Our Transition Process

- Attended the City of Albuquerque Summer Job Fair 2019
- Albuquerque Job Mentorship Program
- Worked in food service
- Applied for Dynamy Gap Year Program
- Worked in retail
- Applied for Division of Vocational Rehabilitation (DVR) services in April 2021
- Catherine graduated in May 2021
- Catherine begins to receive DVR services in June of 2022
- Challenges with community college classes, jobs

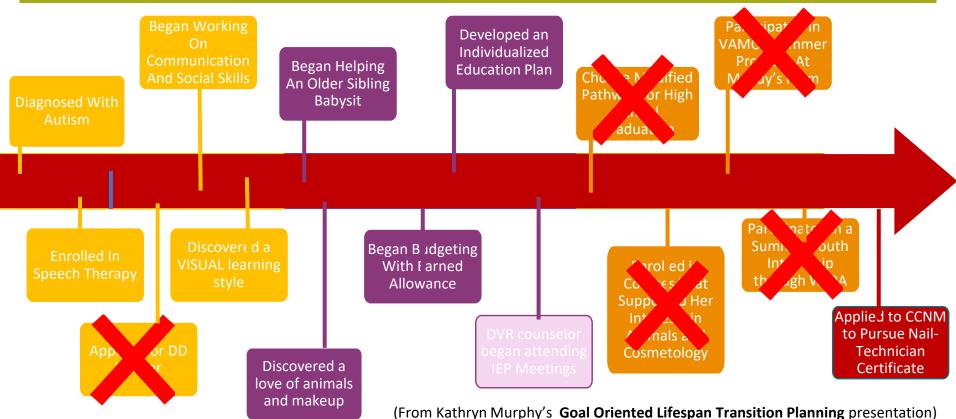


The beginning of this journey

- Sharing with a friend the struggles my daughter was having with employment
- Participated in a couple of PFE trainings
- Signed up to attend the PFE Supported Employment conference in 2023
- Kathryn Murphy: Goal Oriented Lifespan Transition Planning
 - * The presentation name says it all!
 - * I didn't understand DVR's place in the transition process from age 14 forward
 - * Each piece of support fits into a scaffold



Grace's Transition Timeline





Challenges with Transition

- I didn't understand what DVR could offer
 - * I knew they offered some help in getting a job, but not any details
 - * DVR representative in IEP
 - * Online transition fair 2021
- After graduation, we didn't have a network of trained transition supporters
- I was busy with life!
- My daughter wants to be an independent person!

Like many other things in life, you don't know what you don't know.



Catherine Disability Services

Division of Vocational Rehabilitation (DVR) services

- * Job Coaching (LSG Untapped Program)
 - Resume, Job search sites, Interviewing
 - Social Group
 - Working with a Speech Therapist--communication skills
 - Avail app
 - On-the-job support
- * Laptop Computer (DiverseIT)
- Driving Lessons (Driving to Independence)
- Supplemental Security Income
- Does not receive DD Waiver services



The Rehabilitation Process

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Plan Development

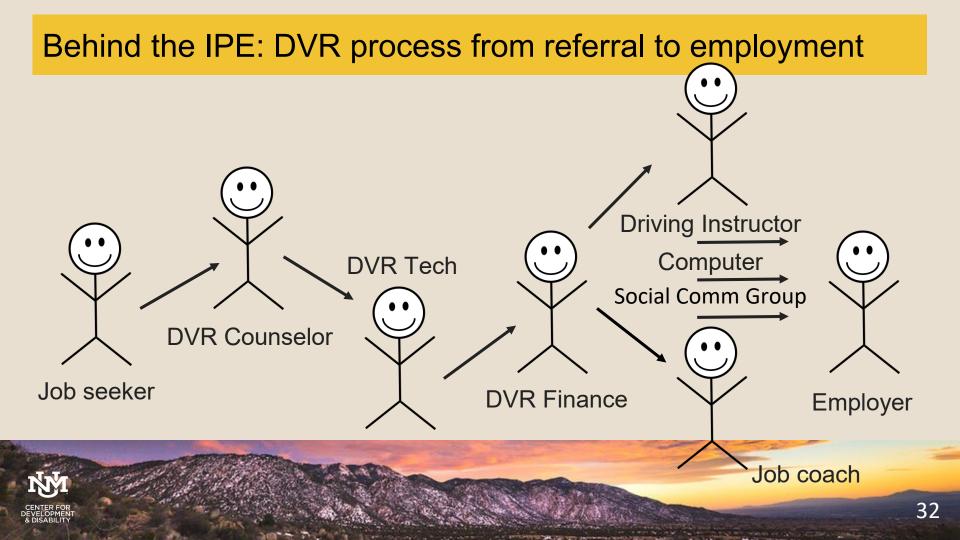


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Eligibility

Employment placement











Source: https://smart.servier.com/

Source: Freeimages.com





Let's Talk About Language

- Language is contextual
- Different communities have different meanings for the same words or acronyms
- If you join a community, you need to learn the language
- You learn better if longer-term members of a community realize you do not automatically know the language
- Teachers of the terminology define terminology along the way and check for understanding



What communities are you a part of that have different language?

Now we'll look at different words and acronyms.

How does community and context change their meaning?



DVR

- Division of Vocational Rehabilitation
- Digital Video Recorder
- DV: Domestic Violence



Transition

- 1. the process or a period of changing from one state or condition to another. "Students in transition from one program to another"
- 2. the process by which a transgender person permanently <u>adopts</u> the <u>outward</u> or physical characteristics that match their gender identity, as opposed to those associated with the sex registered for them at birth. The process may or may not involve measures such as hormone therapy and gender <u>reassignment</u> surgery.

"she had been living as a woman for eight years at that point and had completed her transition in 2001"

(Results from Google search)



POTS

- Something in which you cook food
- Something in which you plant plants
- Postural Orthostatic Tachycardia Syndrome

Postrual: pertaining to position

Orthostatic: to stand up

Tachycardia: increased heart rate

<u>Syndrome</u>: a groupd of symptoms that consistently occur together



Do you speak up when you don't understand a word, phrase, or acronym?



Think Like a Parent: HS and Young Adult Transition

- How can a client know what options for service are available to them?
- How can service providers make sure their client understands "to dos" when leaving a meeting?
- How can client as well as parent/other advocates for a person stay informed of "to dos" and progress?
- Would providing specific follow-up help with the outcomes for young people?
- How do we help people know what they don't know but is important for them to know?!!?



Lessons Learned & Tools and Resources: High School Forward

Recommendations	Tools & Resources
If at all possible, have client attend sessions (with DVR counselor, with service providers) with an advocate (parent, etc.)	DVR counselor, service providers can clarify information and client has two sets of ears
Check for understanding	Service providr asks client/advocate to summarize discussion points
Provide "to dos," follow up (note: executive function challenges)	Service provider makes "to do" list and follows up with client



Recommendations	Tools & Resources
Process to track start of services	DVR counselor, tech can let client know where submission of service request is in the pipeline
Explicit "menu" of resources, with descriptions, links (ex: job coach list, list of other services available)	Use resources such as <u>NMFinder</u> , example of listing: <u>Visions New Mexico Community Resources</u>



What is Catherine Doing Now?

- Continued health issues (POTS, gastroparesis, hearing)
- Driving lessons; would like to buy a car
- No more social group
- Computer she received had issues





What is Catherine Doing Now?

- Worked at her current job since September
- Finishing at CNM: ??
- Would like to go to 4-year college and get an education degree
- Would like to get married, have kids, live in her own place





Conclusion

- People with invisible disabilities in many cases need more supports in addition to what is already provided by the school system and disability service agencies
- Communication is key
- Try to see the world through a parent's eyes when providing guidance and services



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Resources

La Dawna Pea (LSG) Erin White Canales (LSG) Nathan Winham (LSG) Aaron Anderson (LSG) David Marsico (LSG) Kathryn Murphy (APS) Joanne Tippeconic (APS) Anthony Harkness (DVR) Juliana Lujan (DVR)

The **Challenge: Besting Disability** team:

Brenda Borek, Pam Clark, Maria Claudet, Margaret and Matt Luke, Julie March, Renee Reynolds, Nicole Sy, Sandy True

The PFE team, especially Alex Rios and Naomi Sandweiss Willie



Resources and References

Job Mentoring Program (JMP) Brochure

LSG Untapped Program

NM DVR

Parents Reaching Out

Partners for Employment





Questions?

Thoughts?

Ideas?

