

### Introduction

For the last 15 years, ThinkWorkStories! has been studying and developing stories about the practices and strategies that support people with intellectual and developmental disabilities (IDD) to live and work successfully in their communities. The stories are based on interviews of youth and young adults with IDD, service professionals, and family members. Families are a pivotal support system for children and youth as they grow and explore the world around them. For youth with IDD, the involvement of families is instrumental in helping them lead meaningful and fulfilling lives.

Research has consistently demonstrated that even though family engagement in the employment process is considered a best practice, it can be challenging for families and professionals to work together (Baker et al., 2016). Research has also shown that family engagement can be even more challenging for individuals and families who are marginalized because of race, ethnicity, language, socioeconomic status, immigration status, and culture (Wilt & Morningstar, 2018). This brief shares the perspectives and experiences of culturally and linguistically diverse family members of four youth who shared their employment and community engagement stories. It outlines the pivotal role these families played to support youth with IDD to find and maintain competitive integrated employment and to meaningfully engage with their communities. It draws from in-depth, semi-structured interviews with youth with IDD, their family members, and job coaches.

Our findings center on discovering and nurturing individuals' strengths, the importance of family support, and the importance of partnership with service providers to overcome barriers to

accessing employment services and supports. We present the family members' perspectives to foster communication and partnership between professionals and family members about what each side can offer in the interest of supporting the community life and employment goals of people with IDD.

### It Starts with the Family

Family support was instrumental to the youths' employment and community engagement journeys. Support manifested in various ways for the families interviewed, from creating an environment where youth with IDD were expected to live and experience life like their siblings without disabilities, to the belief that youth with IDD were not limited, that they could develop skills and work in any field that they choose to, like everybody else. Next, we share a few examples of what families did to support the youth.

#### High Expectations:

A central theme from all the interviews is that families had expectations from the start that their youth with IDD would have the same opportunities and experiences growing up as their peers without disabilities. Therefore, finding employment in the community was part of the expectation. For example, a mother shared her daughter's experience in finding her first job, emphasizing the importance of setting high expectations and offering equal opportunities. She shared:

*"We realized that [my daughter] was at the age that other kids work. We have a daughter who's older and she started working when she was 14, and we wanted to provide the same experience for [her]. Although she has a disability, it doesn't*

*mean that she's disabled. She needs to have the same opportunities as everybody else. I always say that we have to have high expectations for our kids .... we want to make sure that it starts with us. And if we don't... nothing is going to happen; nothing."*

Subsequently, the youth interviewed lived up to their families' high expectations and pursued their interests and employment goals. The youth shared their aspirations to work in different fields and to contribute to their communities, including as an assistant teacher, a motivational speaker, and a medical office administrator. The youth also shared their plans to develop skills and gather the experience needed to propel them toward their desired career choices, even as they worked in their current jobs.

### **Fostering Pursuits and Interests:**

The families' unwavering support for their youths' interests laid the foundation for positive employment and community engagement outcomes. As one mom put it, *"It does start with the family a little bit, just allowing that person to be open with the possibilities...."* The mom shared how the family followed the youth's lead and supported him to pursue his interests in various things, including in cars, trains, and photography, all of which *"empowered him to think that he's not limited."* Because of this investment, the youth was able to turn one of his interests—photography—into a business. The family also worked with schools and providers to follow the youth's lead, resulting in employment opportunities aligned with his interests and passions.

Another mom shared how she supported her daughter's passion for helping and motivating others by assisting her to start a book club to help improve reading and comprehension skills for young, first-generation immigrant children at her church. The mom and the daughter reported that the book club helped the daughter contribute to and become more integrated in her immigrant and church community. As the daughter shared:

*"You know, before, people had their misconceptions about me. And then they figured out: "Oh, she's smart! She's in*

*college! She can have a good conversation. Now, especially after I did the book club for the kids, my church community is very supportive.... The parents are very understanding now because when I did the book club with the kids, I would give them updates on how the kids are doing after the book club. So since then, the parents see me more for me and not just my physical disability, which is awesome."*

Yet another mom discussed how she supported her daughter's interest in modeling for her recycled materials clothing fashion shows. The modeling opened doors for the daughter to engage with her community, to be part of her culture, and to give back to her community during a global pandemic. Her mom noted:

*"I made a dress that was not made for her, it was made for somebody else. She wanted to wear it, she was happy and when I saw that, I thought, my God, my daughter shines! My daughter loves this. She's being part of the community. People wanted to take pictures with her, and she was shining out there. So, I was like, OK, if she likes to do that, why not, it was giving her opportunities. ... And it was part of teaching [my daughter] about my culture.... During the pandemic, she also did a runway show to the people in our neighborhood. Here she's wearing different clothes. One dress a week for our neighbors who were outside waiting and doing nothing."*

These stories highlight how championing the youths' hobbies and passions did not only empower the youth, but also propelled their interests into meaningful contributions, facilitating their employment and integration in their communities. By nurturing their passions, families empowered these youth to transcend perceived limitations and embrace diverse interests.

### **Skill Development:**

Families explained how they supported youth to develop the necessary skills for employment and community engagement. They encouraged volunteer work, academic pursuits, and

extracurricular activities that helped build valuable skills and relationships. For example, one family described how they supported their youth to volunteer in outdoor activities and service projects with her local Boys and Girls Club and with Girl Scouts. In addition, the youth enrolled in a program that allowed her to take community college classes while in high school, which helped her acquire excellent Microsoft Office and Adobe Photoshop skills.

Another family supported their youth to work as a volunteer assistant art teacher and an assistant music teacher while he was still in high school. Further, two families discussed hiring private providers to help the youth develop specific job and academic skills.

These opportunities to build skills and create relationships shaped the youths' career paths and aspirations, helped them build their resumes, and opened other opportunities for the youth to get paid internships and jobs.

### **Families Believed in Youths' Contributions:**

Fundamentally, the families firmly believed that youth with IDD had valuable contributions to make to society, just like anyone else. As one mom put it, "Everybody has something to contribute... everybody wants to work—not to work just to work, but ...to be able to contribute." Another mom shared how her daughter did fashion shows in their neighborhood during the global COVID-19 pandemic quarantine, providing a meaningful leisure opportunity for her community. This belief in youths' contributions played a vital role in enabling these youth to be an integral part of their communities in meaningful ways.

### **Families Collaborated with Service Providers:**

Collaboration with service providers was a key strategy employed by families to help youth explore non-traditional employment opportunities. Families described how they partnered with providers to think creatively and identify unconventional employment opportunities. One mom shared how she had worked with a provider to think outside the box to explore non-traditional employment opportunities, something that was previously uncharted territory for the

provider. This helped the youth get a paid summer internship with the Department of Conservation and Recreation, which was outside of the provider's purview. While the mom found the internship opportunity, the provider supported the youth through the interviewing process and ensured the youth had the necessary supports to succeed in the job. Then, the mom provided transportation to the job. These partnerships facilitated internships and job opportunities, which expanded the youth's horizons.

## **Challenges Families and Youth with IDD Faced**

The families shared the challenges they encountered while supporting their youth to find and maintain employment and community engagement opportunities. These challenges included discrimination, low expectations, and navigating unfamiliar service systems.

### **Discrimination:**

Families shared how discrimination often stood in the way of employment opportunities, despite the youths' qualifications. One mom shared that, although her daughter is multilingual, had volunteered since high school to gain experience, and is therefore qualified for most of the jobs she's interviewed for, she often was not picked for the jobs. The mom shared:

*"She has a lot of experience... even though she has intellectual disability, she volunteered at a very young age, just like all the other kids without disabilities. But until now she has never found a full-time job yet. [My daughter was] very frustrated and disappointed about our communities that keeps talking about diversity, equity, and inclusion [while] for the disability community, you can tell the unemployment rate is very, very high."*

The mom talked about how her daughter's intersecting identities as a person of color who also has an intellectual disability exposed her to more discrimination. She called on everyone to advocate for the implementation of more inclusive employment practices. She noted that for this

purpose, the daughter had applied and was accepted in the Young Adult Leader Fellowship at the Massachusetts Advocates for Children, to advocate for change in the disability field. The mom noted:

*“I just want to say that we really have to advocate for the disability community to gain more employment opportunities, training opportunities, you know going to college opportunities. [My daughter] is applying for the fellowship at the Mass. Advocates. Why? ... to go talk to attorneys, talk to lawmakers, talk to law enforcement officers, to have them modify the law to give the people with disabilities more employment opportunity, training opportunity. They cannot be totally left out.... we just want to advocate. If nobody’s going to do that, they will just be totally left out.”*

### **Low Expectations:**

Low expectations led to restricted educational and vocational choices, requiring families to advocate for equal opportunities. Families shared experiences where others presumed their youth were incompetent. This manifested in various ways, such as the assumption that youth could not take certain courses in school/college or that they could only do certain kinds of jobs. For example, one mom shared how a community college did not allow dual enrollment students to take academic courses. She therefore had to advocate for her daughter to be allowed to take an academic course at the college like everybody else, and not to be forced to take a recreational course just because she had a disability. The mom shared:

*“They don’t allow [student with IDD] to take some academic classes and I fight with them very hard and eventually they allowed [my daughter] to take the computer application class and Adobe Photoshop class. Because they just ask the kids to take something like a music class or some kind of recreational class.”*

The opportunity to take the academic classes enabled the youth to develop computer application skills in Microsoft Office and Adobe Photoshop, which is useful for the youth’s employment goal of working in a medical office. Commenting on her advocacy efforts, the mom noted, “You just have to keep following up ... if I do not advocate, no one will help my daughter.”

Another mom shared how schools and employment providers were steering the youth toward particular jobs that have traditionally been categorized to be a good fit for people with disabilities. She shared that:

*“Schools are pegging them into specific positions. And I knew there was a young man and when [my son] was at [high school], ... and he wanted to be a firefighter. But they were just like, oh well sorry, we don’t have a pathway. Like, they don’t even try to create it. ... it’s almost like we only have our network of... you get to do recycle or whatever. And there’s nothing wrong with that; don’t get me wrong. But they [the youth] really do have specific interests. I think if the interests are not part of the provider’s network, they don’t even pursue it. Like sorry, you can’t get that job. You can only get these.”*

This mom shared how she worked with the school and employment providers to find a job that aligned with the son’s interests.

Unfamiliar Systems: Another key challenge was navigating unfamiliar service systems, especially for immigrant families and those not fluent in English. Families interviewed shared how they often did not have adequate information about resources and supports available to their youth with disabilities. For example, one mom discussed her struggle navigating the service system as an immigrant and a person of color whose first language is not English as she advocated for her daughter. She shared:

*“I knock many doors, many, many doors, and some of the doors slam in my face, some other doors open. But that didn’t stop me from supporting my daughter.”*



*And I'm talking in many diverse settings: with doctors, at the school. And you know how it is, the navigation for a mother, especially when you don't speak the language, especially when you are a person of color, and when you have so many things going on; your family members, your community..."*

All the families reported facing various difficulties navigating the systems and getting the necessary support. As a result, two of the families interviewed had to hire private providers to provide supports for their youth.

In addition, families also shared how they had to constantly follow up with providers to ensure their youth received the necessary services and supports. As one mom put it, "You have to basically keep up with—you always have to follow up. If you don't do something, then they will forget you." She shared that sometimes providers were difficult to reach, and they could go for months without receiving services. Eventually, the family would have to go back to the state agency before the provider assigned to deliver services responded.

Relatedly, families shared how they continuously looked for information from various sources as they did not have a formal source of information about the resources and supports available for their youth. As one parent put it:

*"I will find anything that's going to help [my daughter]. When someone tells me something, I immediately go to do research...If you don't follow up, no one is going to tell you. ... so, I just have to find all these different resources for [my daughter]."*

## Conclusion

Families serve as the bedrock for supporting youth with IDD in their quest for employment and community engagement. Their unyielding support, advocacy for equal opportunities, and collaborative efforts with service providers play a pivotal role in shaping the trajectory of these individuals. Despite facing various challenges, families persistently advocated for inclusivity and worked tirelessly to overcome barriers, ensuring their youth got employment opportunities to engage and contribute meaningfully to society. Here are some suggestions for families as they work to support their youth:

- Hold high expectations for your youth with IDD, emphasizing the importance of equal opportunities and experiences in both employment and community life.
- Empower youth with IDD to explore their interests, nurturing their passions and enabling them to contribute to their communities.
- Actively support youth to develop skills needed for work and community participation, using volunteer activities and educational programs.
- Believe that people with IDD have valuable contributions to make to society and partner with service providers to explore diverse employment opportunities.

## References

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