



How Families and Employment Professionals can Form Partnerships to Support Youths and Young Adults with Intellectual and Developmental Disabilities (IDD)

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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 with 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, families play an important role in supporting them to live full and meaningful 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. Our findings center on discovering and nurturing individuals' strengths, the importance of partnering with service providers, barriers to partnering with service providers, and strategies to improve collaboration between families and service providers. Our intention in presenting the family members' perspective is 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.

This brief highlights the perspectives and experiences of family members of four young adults with IDD who shared their employment and community engagement stories. It outlines the roles their families played to support them to find and maintain competitive, integrated employment and to engage meaningfully with their communities. It draws from in-depth, semi structured interviews with young adults with IDD, their family members, and job coaches. In all four stories featured in this brief, the mothers of young adults with IDD were the family members who agreed to be interviewed.

Discovering and Nurturing Strengths

When the young adults were children, the mothers wanted them to contribute to their communities in similar ways to their siblings and peers without disabilities. They looked for their emerging qualities and interests, sometimes discovering them on their own or having other people point them out. One mother who made and sold clothes described how she discovered and nurtured her daughter's interest in modeling the clothes as a way for her to be part of the community.

"I was the one who says, 'No, I don't want her to model.' I didn't know how she was going to do the job. And I was working in collaboration with another girl who was doing the tops and I was doing the bottoms. And she's the one who says: 'Just give her an opportunity. She can model for me.' And then 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 so comfortable. She's being part of the community. People wanted to take pictures with her, and she was shining there. So, I was like, OK, you know what? If she likes to do that, why not? It was giving her opportunities."

Other mothers commented on how they had begun to discover their young adults' interests at an early age. One mother described how her son developed his photography skills, which led to him feeling more connected to his school.

"He's taken up photography completely on his own and he's done that at school. I think that's probably why he has such a connection to them (the school) because they just took that skill and kind of went with it, thought outside the box."

The feeling of connection to the school influenced him to develop a goal of becoming a teacher.

When their young adults were teenagers, the mothers nurtured meaningful opportunities for them to contribute to their communities. The mother of a young woman who loved to read and to motivate



people supported her to communicate with others on the Clubhouse app and led the family in helping her run a children's book club in their home. In the case of one youth who was social and wanted to be helpful, the family engaged her as a volunteer with organized group activities, such as Girl Scouts and a Boys and Girls Club.

In the other cases, the mothers advocated to ensure that their youths had opportunities to explore their interests. Here are some examples of the steps they took:

- ▶ Initiating a discussion with a teacher about how one youth could participate in the school's senior year internship requirement.
- ▶ Advocating with service professionals to allow a youth to take classes in line with a career goal instead of the standard classes offered to students with IDD by a community college.
- ▶ Learning from a store manager about a youth's support needs on the job and hiring a job coach to provide guidance.

The mothers highlighted their young adults' soft skills. Through their day-to-day life experience with their young adults, the mothers could identify their strengths, personal qualities, and aptitudes, including how they had come to rely on their positive contributions to family life. One mother described her son as being time-oriented and a planner. Another mother described her daughter's heart of gold, great work ethic, and ability to find anything other people had lost at home. A third mother depended on her daughter's sense of responsibility for her siblings, *"Well, she is like a mini mother in the house, so she puts the other kids in check. You know, when I'm not around, I don't feel like anything could go wrong."*

Importance of Partnering with Service Providers

The mothers wanted professionals to know that they appreciate the services and focus available to their young adults while enrolled in high school.

Strong pre-employment training. The mothers valued the services available to prepare their young adults to transition from high school to adult life. These services included employment-related classes and occupational, physical, and speech therapy. One mother said that her daughter took pre-employment training over and over to be ready for her first job. Another mother said that both her son's high school and post-school day program helped him learn about interviewing for a job and workplace soft skills,

and that the trainings that used video modeling were particularly helpful for him.

Building trust and rapport. The mothers valued professionals who took time to listen to and learn about their young adult and the family and who then acted upon their suggestions when considering employment goals and opportunities. A mother who developed a sense of partnership with the job developer appreciated that the job developer consulted her and was open to developing employment opportunities with community partners who were new to the service provider. As a result of the relationship, the mother shifted her own thinking about a training the job developer recommended, realizing it might be more useful to her son than she had previously thought because of the employable skills he would gain.

Barriers to Partnering with Service Providers

Limited information about services. Most of the mothers expressed the view that they did not know much about what services were available for their young adults or what they could ask for. Two mothers talked about gradually finding out the eligibility requirements their young adults had to meet to receive employment supports or funding. Two mothers described exchanging information with the parents of other young adults with disabilities who were also looking into what was available. One mother commented that following up with case managers and job coaches was difficult and that this might be due to high rates of job turnover. She described learning that funding for services would be easier to obtain if her daughter were in a day program but was researching other funding sources since the family preferred that she be working and in the community. She described gathering information wherever she could:

"I just have to find all these different resources for her. I think I can be the special education consultant [laughs]. I will find anything that's going to help her. When someone tells me something, I immediately go to do research."

Limited availability of community life and employment support staff. To meet their high expectations, the families concluded that they needed to be involved in either providing direct support or finding alternate support outside the service system.

The family of a youth who began working while still in high school discovered that employment support services would not be available to her until she had

completed school. The mother described how her family stepped in to support her daughter's first job at age 14:

“So, we realized that [she] was at the age that, you know, other kids work. We have a daughter who's older and she went through the process of working since she was 14 and all the things that teenagers do, you know. And we wanted to provide the same experience for our younger daughter. Although she has a disability, it doesn't mean that she's disabled. She needs to have the same opportunities as everybody else.”

We started looking to provide the same opportunities, age-appropriate, and it was a lot of research. What they say is ... they would give more support once the kids are 22 or after school. So, it was us who did all the pushing and talking to the supervisor and making sure that she had the skills. We needed to hire a private coach to come in and support her on the job.”

Services were also limited on a day-to-day basis. One family discovered that job coach services were not available after hours to support a young adult who worked during evening or weekend shifts, so support came from other employees and at home from family members. In another case, a student who needed transportation support could not coordinate the available transportation times with her class schedule in college, so her mother and sisters arranged a transportation schedule.

Need for expanded employment training options. In two families, the mothers believed that the employment training classes offered to their children did not lead to in-demand careers. One mother commented on how unprepared she and other parents in her network thought special education students with IDD were for the jobs available in their communities.

“We just feel that they don't give these kids appropriate skills training, so when they're out of school they don't have any skills. That's the thing I think our current high school special education should consider. Give them a skill training program, you know, like certified nursing assistant program or pharmacy technician, like patient care technician. They could do very basic stuff, so that's the thing.”

Another mother spoke about working with her son's job coach around the limited employment options offered through the school and the day program her son attended:

“I think that's the part that's kind of hard, is like, schools are pegging them into specific positions. And I knew there was a young man 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 recycling or whatever. And there's nothing wrong with that; don't get me wrong. But they really do have specific interests. I think if the interests are not part of the school's network, they don't even pursue it. Like sorry, you can't get that job. You can only get these.”

Out of date beliefs and low expectations. In three of the four families, the mothers described encountering out-of-date beliefs and low expectations about people with IDD expressed by others, including community members, educators, and potential employers. One mother believed that these attitudes were causing her young adult to experience employment discrimination. All the mothers felt that low expectations for people with IDD is a societal issue. Each mother described the skepticism and negative attitudes she had faced from others about her young adult's potential. While the mothers did not necessarily know one another, they all shared a similar technique of preparing for discussions about their young adults and gathering examples and concrete proof of their abilities to refute any doubts or misconceptions others had about their young adults. During the interviews, the mothers presented pictures of their young adults engaged in activities they had described, charts of their progress, and letters from teachers or others who had supervised them in work situations. This documentation was especially important to a mother who was trying to convince a job developer that her son was, in fact, accurately reporting some work experience as a teacher's assistant.

“It's funny because when he interviews with the schools, ... they keep saying: What's your experience? He's like, I've been doing it for several years. And they were like: You can't say that. I was like: No, he really has been doing it for several years. He was the assistant to the music teacher. So, he was handing out the instruments, helping him prepare for the class that comes in. Like, he actually has been an assistant teacher.”

Strategies for Employment Specialists to Consider

Of course, the focus of planning and services is the youth or young adult with IDD. However, engaging with a helpful, invested family member might also help you reach a successful outcome for that young adult. Here are some suggestions for including a family member:

- ▶ **Actively engage the family member in the planning conversation.** You can do this in different ways, depending on the wishes of the youth or young adult, the family dynamics, and the interest level of family members. Communicate in several different ways that allow the family member to attend and contribute to individual education plan (IEP) meetings and employment planning conversations.
- ▶ **Be curious about the young adult's family and community life.** Find out how the young adult contributes to their family and friends' lives to better understand their strengths. Find out how the family has encouraged or observed the young adult's strengths and ask the family to share specific examples of the young adult's accomplishments and current interests and activities.
- ▶ **Learn about transferable skills.** Work with the family to understand how the young adult prefers to learn and complete tasks. Be sure to ask about any training on practical and soft skills that could transfer into the workplace, and any successful techniques family members have used to work on these skills with the young adult.
- ▶ **Learn about the young adult's problem-solving skills.** Find out how the young adult, alone or with support, has solved a problem or achieved a goal related to employment or community life engagement to help you understand their capacities and support needs.

- ▶ **Learn about the vision that the young adult and their family have for their future.** Ask about the young adults' short- and long-term goals and any steps that they've already taken toward achieving them, including how the family has supported or advocated for the young adult. Use active listening skills to demonstrate understanding, establish rapport, and build trust with family members.
- ▶ **Communicate about expectations.** Take time to learn about individual and family expectations for the service system and explain the services and supports you can offer in terms of those expectations. Be especially clear about eligibility requirements, such as age or educational status, for supports and services.

Conclusion

Engaging family members in the job development process for a young adult with IDD can enhance understanding of the job seeker's skills, talents, and aspirations. This is especially true if the family member has provided consistent support and advocacy to the individual, and the individual values the family member as an ally. Ultimately, when family members and service professionals establish a strong working relationship, both contributing their innovative ideas and aligning in their commitment to supporting the young adult's success, the youth will benefit.

References

- Kramer, J., Bose, J. & Winsor, J. (2018). Families and Employment of People with Intellectual and Developmental Disabilities: Results from a Scoping Study. *TASH Connections*, 42(4), 35-45.



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