Circles of Support and Self-Direction
An Interview Highlighting a Journey of Friendship and Managing Services

Elissa Lockman Turner, MS[1], Sarah Bubash, M. Ed[2], Micah Fialka-Feldman, Cert.DisStud[3], and Andrea Hayes, B.S[4]

Abstract: All people need different supports to be successful in their daily lives. For individuals with intellectual disabilities, support needs have traditionally been agency-directed. Circles of Support shift the control over who identifies and directs those support needs from an agency-directed model to a self-directed model, putting the individual with an intellectual disability at the center of a self-selected team of individuals involved across all environments in their daily life. By reconceptualizing how individuals identify and receive supports, individuals are given the control and agency needed to live a self-determined life. This interview is with two people working together in a different way from traditional agency-directed supports, shifting control over decisions from the provider agency to the person with a disability, allowing for greater control over all areas of his life.

Keywords: intellectual disability, Circles of Support, self-determination, self-direction, supports model

W e live in an interdependent society, where all people need and use supports in their daily lives (Thompson et al., 2009). People may receive supports informally (i.e., friends, family) or formally (i.e., paid supports such as health care providers or hair stylists). The type and degree of supports people need vary depending on the individual and the environment (i.e., home, work, school) in which they are interacting. Just as the supports of individuals without disabilities vary depending on the environment and activity, many people with intellectual disability receive some mix of formal (i.e., government-funded,

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eligibility-specific paid supports) and natural (i.e., unpaid or informal) supports (Reynolds et al., 2018). Luckasson and colleagues (2002) define supports for people with intellectual disability as "resources and strategies that aim to promote the development, education, interests, and personal well-being of a person and that enhance individual functioning" (p. 151). When developing a support plan with an individual with intellectual disability, it is important to examine how the individual can receive natural supports in addition to formal supports. Without such considerations, people with intellectual disability can experience low expectations and lack of meaningful experiences within their communities (Lord & Hutchison, 1993).

In 1980, unhappy with the type of support she was receiving, Judith Snow, a woman with quadriplegia, developed an innovative way to reconceptualize and receive supports by establishing the first documented Circles of Support with a group of her friends (Pearpoint, 1991). Circles of Support are now used as a way to formalize and identify support needs by bringing together important people chosen by the person with a disability (Macadam & Savitch, 2015; Wistow et al., 2016). This type of support system gives individuals with disabilities the control they need to live in inclusive communities by aiding the individual in their advocacy to receive formal supports along with promoting self-determination and choice (Araten-Bergman & Bigby, 2021). Circles of Support are self-directed by the individual with intellectual disability, allowing for greater control over all areas of their life. Self-directed supports are different from traditional agency-directed supports in that the control over decisions is shifted from provider agencies to the person with a disability (DeCarlo et al., 2019). Self-direction is congruent with the concept of self-determination, which enables a person to have control and

autonomy over decisions and the direction of their life (Shogren et al., 2017; Wehmeyer & Bolding, 2001).

Circle of Supports and self-direction have been used and implemented by Micah Fialka-Feldman since he was in elementary school and continuing through adulthood. He has created a unique Circle of Supports that includes friends, family, and agency providers who support him to make decisions about his life and acquire the resources needed to meet those goals. Andrea Hayes is an Independent Broker in the state of New York where Micah lives. She assists Micah to have control of the public funding for his services, and to be the "boss" as he manages his supports. Here, they have a conversation where they share aspects of their unique relationship and how this type of support enables Micah to continue to make informed choices and develop a truly individualized self-directed plan to live the life he chooses:

Question (Q): Can you explain what a Circle of Supports is?

MICAH FIALKA-FELDMAN (MFF): To me it's people that come together and meet with the person and help them with things that they need help with and challenges they might have in their work on their job and their community. People are coming together and people can come and go—it's not like you have to come to every meeting. Andrea, I don't know if you want to add.

ANDREA HAYES (AH): Sure, I think that was a great explanation. Circles are people in your community, family members from afar, and friends that you've connected with over your lifetime that commonly go to meetings, like you said Micah, who gather to support the individual. People who come together to support this could be paid and unpaid supports and there's multiple different circles that come together at various times. For example, Work Circles or Neighborhood Community Circles for big moves, so it's just a matter of having people to support you.

Q: How did you first learn about Circle of Supports and when was your first Circle?

MFF: My first circle was in 1993, I think, third grade maybe. My parents brought the idea to my school. My parents did more of the advocacy when I was young. I was young, and I didn't know that much to advocate. I just, I just went to school and was doing my thing. But I learned about it from a group in Canada. It's the Inclusion Press. I'm not sure if you've heard of them but they've been doing Circle of Friends and inclusion for many years, and I learned about it from them and about how people started Circles.

Q: How did your Circle of Supports change throughout your years in K–12 school and what did you learn along the way?

MFF: When I was young it was my friends. My social worker would ask the kids to raise their hand to join my Circle. We would meet during lunchtime and would have pizza and play kickball. Fun activities. In middle school we had some meetings,

just to help me with what was going to happen. Sometimes it didn't go as well. Like one time, we would meet at 3:30 after a long day, a social worker would only want to talk about things that I wasn't doing well so we had to talk about how that is not what a Circle does. In high school we were trying to figure out how I would take a bus and how I would get up to college, because I don't drive and in Michigan lots of people don't take public transportation because there's a lot of cars. But we found a friend and then she taught me how to take a bus for two times and then I learned how to take a bus from my house to the College. Well, the thing is that when I brought the college idea to my high school lots of people were surprised that I wanted to go, because people like me never went to college and it was a very big thing. I'm glad I had a good teacher and I talked to some of my friends that graduated from high school and some of my friends joined my Circle. I did some directing when I was in high school. When I moved to Syracuse that was when I was more in charge of my Circle and meetings. I decide who I want in my Circle and I get help with that.

Q: What are some of the beneficial things about using a Circle of Support? What are some of the successes and challenges you have had using a Circle of Support?

MFF: I think the successes are when people come to meetings. I had a big meeting because I was not happy and I was trying to decide where I was going to live and I was maybe going to move to Boston where my sister is. But then I got 40 people in my house to have a meeting and it was quite amazing. People shared great ideas and, and I talked about buying my house. I can call people when, when I like need something. I can call people if I just want to talk about something. As I got older, being a supervisor to my staff and learning that is not easy.

AH: I agree, I think the Circle helps people with a disability to move from living isolated lives that are very much controlled by agencies and traditional supports. Micah has gone through all these steps from facilitating his own Circles and preparing an agenda with help and writing down what he wants to talk about and what's the theme of the meeting. He brings that positivity and strength, and I think someone walking in that Circle sees how this is a community full of support and people that care and want to foster his life to be the happiest. So I think it's just a complete shift from the models that previously people are used to seeing.

Q: How did the two of you meet and when did you start working together?

MFF: I wanted to do self-direction and a friend said, "Oh, I have a friend that's a broker" and then I think we met at the agency with one of my staff.

AH: Yes, you called me and said you were receiving traditional services from an agency, and I was managing broker services at an agency. We met and we started this conversation of what you know about self-determination and how you can

expand that concept to taking full control over your funding and services. We talked about how funding for services was managed through programs at agency verses being able to see individualized funding and creatively make your own plan with person central planning. I explained how funds through your self-direction budget could be amended as needed, like if more funding is needed for transportation or staffing. This can provide even more control of services, as human lives can't be exactly planned out for an entire year . . . we can try our best but that's not practical or real life. We started these processes so you can have your own budget. There's an assessment tool with adaptive, medical, and behavior scores that are populated to determine how much funding someone will receive through State and Medicaid dollars. Micah had never seen this form, and his family never saw this form. Previously, this form was completed by a Care Coordinator without working with the people who know Micah the best. By completing it correctly there was a difference of over US$40,000 that Micah should be receiving.

Q: How has working together helped you grow?

MFF: Being a supervisor is not easy. I learned how to get help with challenges and how I have ups and downs, and how I can go to people and get help from other people. And I always remind you to about my budget and all that money stuff.

AH: You're right, it's not the easiest job in the world but I'm sure it is refreshing to know you are not alone with managing your self-direction plan. I'm there to support you with facilitating circle meetings and staff meetings. You went from not being the supervisor to your staff to now being the supervisor of your staff and managing the budget and your expense forms and all that paperwork. I've heard during the staff meetings how wonderful you are as a supervisor. You're awesome as far as your follow-up skills. Your files are never out of compliance and you're always on top of that stuff, asking me what's next. And you're my supervisor—you remind me when my invoices are coming out, and you know to not be late on it. You are an impressive supervisor and I have enjoyed watching you grow into managing all your services and your staff.

Q: How does this type of support relationship enable both interdependence and independence?

MFF: Good support like I get has helped me to learn. I go to them and I have people to ask questions. Other people's thoughts and ideas help me decide what to do.

AH: It's about the supports that the individual needs. But also we all have needs for support. I think it's important to think about how supports make our life better. You can be more successful and independent with those supports. It's important to know when to support when not to support and what people need in their own lives that help them succeed. Independence is something for everyone to strive for, but life is always better with being able to depend on people. It's

important to remember that everyone has the right of dignity of risk.

Q: What do you think is important for people to know about this type of support relationship and what advice do you have for people who want to start to implement something like this?

MFF: I'd say that make sure you have a good Circle and good broker and a good person that knows what they're doing. Think about when you're ready because it is a lot of responsibilities. And some brokers can only meet with you every six months, but Andrea talks to me more. Just make sure you have a good broker who wants to help you.

AH: More people are living independently as we're moving away from all those traditional models. So what happens to people when they live on their own and what happens when family members no longer provide care? Micah has really helped expand my mind, and my interest in being this kind of broker. I see this like a creative opportunity to really enhance what self-direction is and how Circles are extremely a key factor for individuals with a disability to live independently. I would tell people starting new services not to be afraid. It's a lot of paperwork and a lot of responsibility, but it's also a freedom to know you are in control. Establish a Circle and find service providers, brokers interested in building those relationships. It can grow from there. You know, a big part of being in self direction is ongoing educating and training of individuals, families, the communities, really just getting out there and educating about Circles and helping each other, supporting each other in this.

Conflict of Interest

Funding

References

Araten-Bergman, T., & Bigby, C. (2021). Forming and supporting circles of support for people with intellectual disabilities: A comparative case analysis. *Journal of Intellectual & Developmental Disability*, *46*(1), 1–13.

DeCarlo, M. P., Bogenschutz, M. D., Hall-Lande, J. A., & Hewitt, A. S. (2019). Implementation of self-directed supports for people with intellectual and developmental disabilities in the United States. *Journal of Disability Policy Studies*, *30*(1), 11–21.

Lord, J., & Hutchison, P. (1993). The process of personal empowerment: Implications for theory and practice. *Canadian Journal of Community Mental Health*, *12*(1), 5–22.

Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H., Coulter, D. L., Craig, E. M. P., Reeve, A., & Tasse, M. J. (2002). *Mental retardation: Definition,*

classification, and systems of supports. American Association on Mental Retardation.

Macadam, A., & Savitch, N. (2015). Staying connected with circles of support. *Journal of Dementia Care, 23*(1), 32–34.

Pearpoint, J. (1991). *From behind the piano: The building of Judith Snow's unique circle of friends.* Inclusion Press.

Reynolds, M. C., Palmer, S. B., & Gotto, G. S. (2018). Reconceptualizing natural supports for people with disabilities and their families. In M. M. Burke (Ed.), *International review of research in developmental disabilities* (Vol. 54, pp. 177–209). Academic Press.

Shogren, K. A., Wehmeyer, M. L., & Burke, K. M. (2017). Self-determination. In K. A. Shogren, M. L., Wehmeyer, & N. N. Singh (Eds.), *Handbook of positive psychology in intellectual and developmental disabilities* (pp. 49–64). Springer.

Thompson, J. R., Bradley, V. J., Buntinx, W. H., Schalock, R. L., Shogren, K. A., Snell, M. E., & Yeager, M. H. (2009). Conceptualizing supports and the support needs of people with intellectual disability. *Intellectual and Developmental Disabilities, 47*(2), 135–146.

Wehmeyer, M. L., & Bolding, N. (2001). Enhanced self-determination of adults with intellectual disability as an outcome of moving to community-based work or living environments. *Journal of Intellectual Disability Research, 45*(5), 371–383.

Wistow, G., Perkins, M., Knapp, M., Bauer, A., & Bonin, E. M. (2016). Circles of support and personalization: Exploring the economic case. *Journal of Intellectual Disabilities, 20*(2), 194–207.

Bios

Elissa Lockman Turner, MS, is a doctoral student at the University of Kansas, Department of Special Education. She has worked as a paraprofessional, special education teacher, and professional learning facilitator. Her research is focused on addressing environments and practices that support positive outcomes for students with extensive support needs, including the implementation of equitable inclusive education, how environments are built to enable student learning, and effective teacher practices and paraprofessional utilization.

Sarah Bubash was a special education teacher for 10 years before deciding to earn her doctorate in special education at University of Wisconsin-Madison. Her research interests focus on increasing inclusion for students with extensive support needs by preparing preservice teachers that center disabled voices and harness creativity and imagination to support students

Micah Fialka-Feldman is a self-advocate, teaching assistant, outreach coordinator, national speaker, and pioneer who fights for disability-pride, justice, and inclusion. He is part of the first wave of adults with intellectual disabilities who have attended college and has been fully included in school and community. Micah's disability advocacy has a foundation in the creation of the "Beloved Community" and the notion that "A community that excludes even one of its members is not a community at all."

Andrea Hayes has seventeen years' experience providing services through OPWDD (Office of People with Developmental Disabilities) in Central New York. Her professional experiences allowed her to observe and explore a variety of service models, from traditional to self-determination models. Ultimately, she decided to focus on systems change and the creation of person-centered program options through self-direction. Andrea piloted a fiscal intermediary service within a non-for-profit agency to offer Self-Directed services. She subsequently chose to pursue her professional goals by providing independent brokerage, and, thereby, enabling individuals and families to make informed choices and develop truly individualized services options.