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### External Support: The importance of community support in disability healthcare

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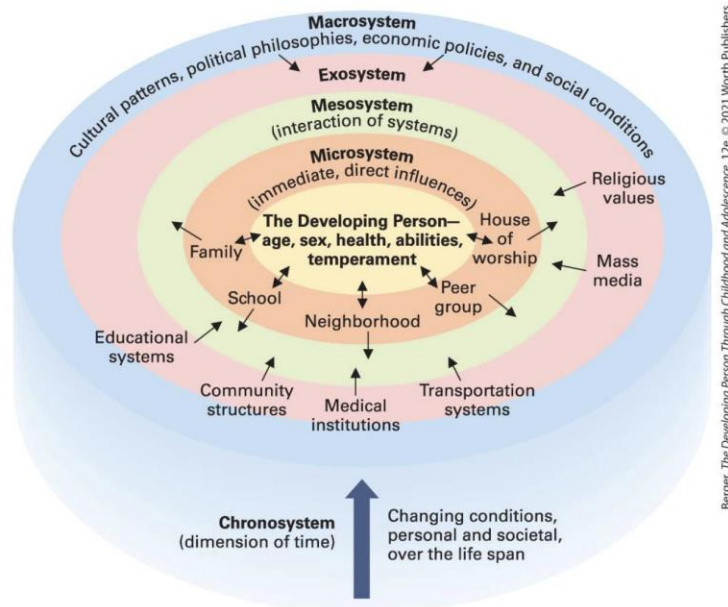
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Kian McCabe

**External Support: The importance of community support in disability healthcare**

Throughout my time at Suffolk University, I learned about many different theories and research studies that talked about the development of people and specialties. One that I found interesting and wanted to focus on was community support for people with disabilities, more specifically in their healthcare. Inequalities in healthcare is a common discussion topic every day in the United States and although most Americans are not able to get the adequate health care, they need one subtopic that I believe that is not discussed enough is disability health care. More specifically the importance of community support and resources in disability health care. My internship this semester was helping lower income families find resources they need for their children with autism spectrum disorder. In this position I learned that many of the positive activities and resources that would be helpful for their children most families are unable to get because they do not make enough money or do not live in a specific area of the city or do not have the time during the day to go to specific appointments. Now with almost 25% of the United States population having a disability along with personal experience in this field it made me think about the importance of trying to bring awareness and give back to those who do not have the resources. We learned as a psychology major that the more support you have as a child and then into your adulthood the more successful you could be at various aspects of your life this goes the same with healthcare if you are supported in your community throughout struggles with your health it greatly impacts the mental health of the person and their support system. The question to be asked is what can we develop to help people with disabilities succeed better in the healthcare system and also support them and their caretakers and families mentally? One

psychological theory that I researched is Bronfenbrenner's ecological systems theory, this area is known to be a strong grounding point on social cultural theory and is the development of the interaction between a developing person and the surrounding society. This theory mainly focuses on the culture that someone grows up in, but it is highly influenced by the support systems they have around them and how they interact. "Bronfenbrenner's ecological systems theory views child development as a complex system of relationships affected by multiple levels of the surrounding environment, from immediate settings of family and school to broad cultural values, laws, and customs." (McLeod, 2023) If these people have better interactions with society regarding their needs and health then they are more likely to develop more successfully overtime. This idea also affects the people around them; many children's parents experience many stressors in their child's childhood if they have less support regarding their child's disability or adaptive needs, this in turn can directly affect the child because the parents' interactions with outside entities impacts the social cultural development of the child. For example, the microsystem is influenced by the mesosystem which then effects the developing person, if a child with autism spectrum disorder grows up to see their parents or guardians struggling financially to get the therapies that they need the parents in turn might take it out on the child and then the child would not develop successfully and it's more likely to have health or mental health issues in the future.



Berger, *The Developing Person Through Childhood and Adolescence*, 12e, © 2021 Worth Publishers

One study that proves these needs is a study conducted in 2022 entitled “Community support, family resilience and mental health among caregivers of youth with autism spectrum disorder”, this study surveyed over 600 families with children who have autism spectrum disorder in the United states to talk about the role of family resilience and community support in the children's and the caregivers mental health. The researchers talk about how “caregivers of children with ASD report lower subjective quality of life, greater depressive symptoms and increased stress compared to caregivers of children with typical development” (Hayes et al. 2019) If the parents are caregivers are suffering depressive symptoms or lower quality of life then the child since that is their support system will most likely suffer the same effects. However, they found in the survey that "Community support was positively correlated with family resilience and caregiver mental health. Bivariate correlations indicated significant positive associations between community support and family resilience. Caregiver mental health, significantly, partially mediated the relationship between community support and family

resilience." (Hayes, et al, 2019). This research demonstrates the importance of having that community support and the resources available to not only get the child the support they need to succeed in the adaptability they need to succeed but also take the burden and stress off the parents to try and find all those things on their own for their child.

So, what can be done? It is vital that we increase community support and resources for children and their support systems not only in the community but also in the healthcare system. Another issue to try and combat is the struggle with youth transitioning to adulthood. One thing that is important to remember is that if these children struggled with health care resources as a child, then when they transition into adulthood, they most likely will have issues as well. One study in Ireland on transitional youth with cerebral palsy children talked about how "However, it has been reported that health service use by individuals with CP decreases following transition from child to adulthood, possibly because of lack of available health service." (Manikandan et al., 2022) this could stem from not only the lack of available health service but also the lack of support that they could potentially have.

But there are ideas that are currently being put in place for adults that could potentially be used for children as well. In a youth perspective piece, the author talked about how there are current resources that are trying to be put in place to add support for the youth. "In Ohio, a current project is underway within the Department of Health to pull together transition resources from across the state and publish them in one central online portal." (Fogel, 2022) having those resources in one central portal could be useful to caregivers because they can spend less time searching around different places for different resources. This is an idea that can be used for younger youth to add to their support system. Also, places where parents can look at other parents' experiences or try out different information can also be useful because it proves to them

that they're not alone in the experience and gives them the opportunity to see resources that might not be publicly available. Places such as foundations run by families of people with disabilities or activists can be very helpful and something we could definitely use more of. Also, having programs embedded in hospitals and schools where families can go and ask for help and support such as the Autism Program at Boston Medical Center or a pediatric specialty program a place that has specialists who know about the resources out there and is able to share them with others. But these programs should not be focused on one specific disability or disorder and should be opened to many people to gain different perspectives.