

THE CHALLENGES OF PROVIDING CARE FOR INDIVIDUALS WITH DISABILITIES: A FATHER'S PERSPECTIVE

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FOCUS OF DISCUSSION

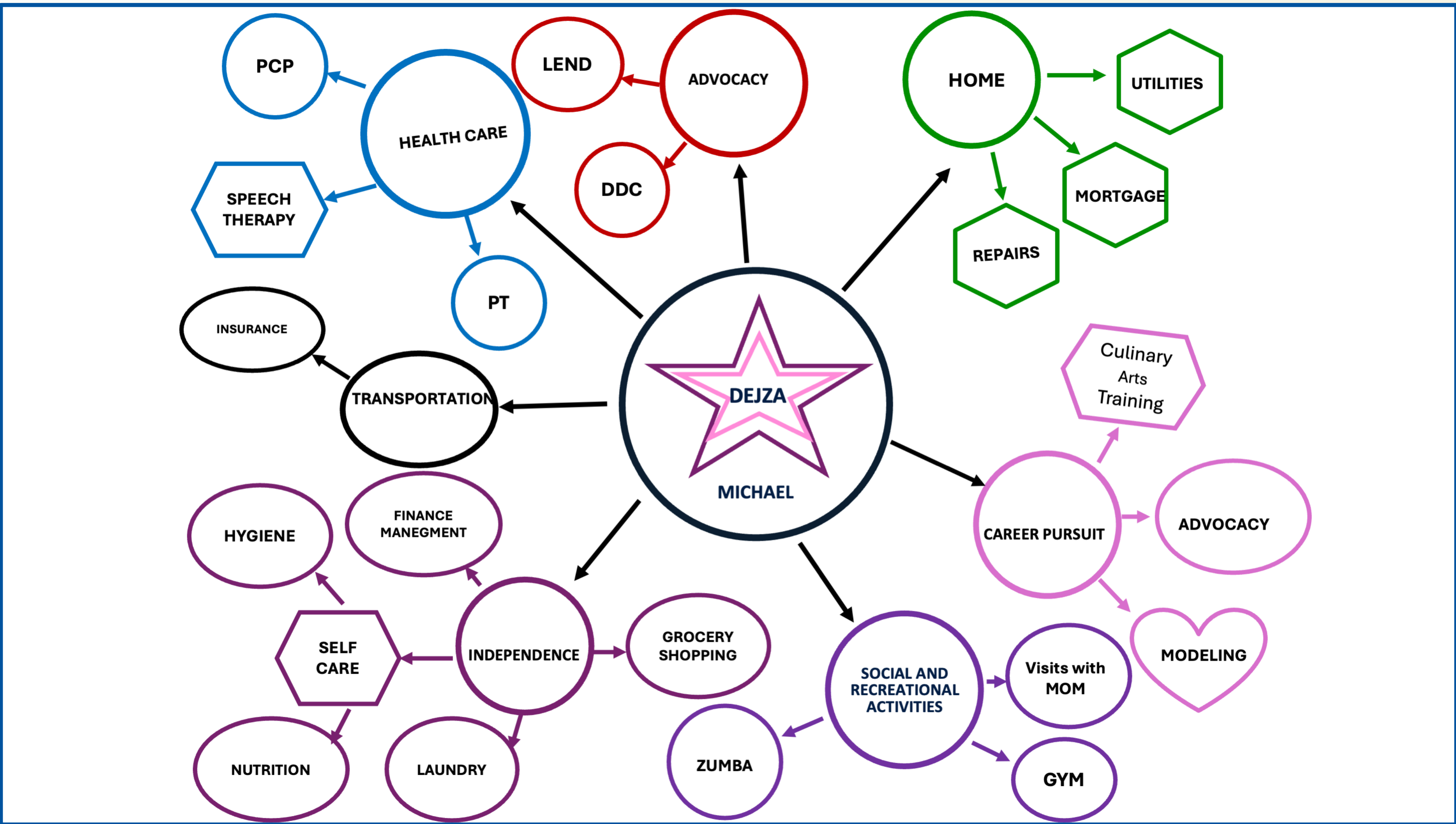
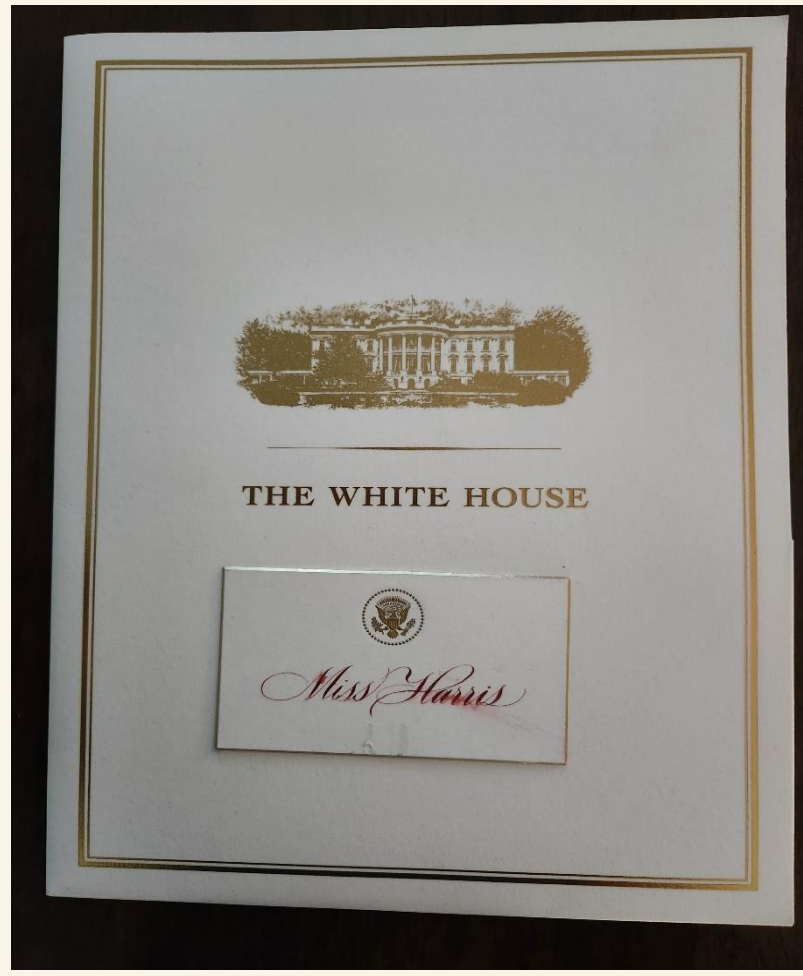
Family caregiving is a 24/7 commitment, unlike a typical nine-to-five work schedule. This continuous care for a child or adult with a diagnosed disability results in expertise that only the family caregiver can provide. However, the expertise derived from continued care is often undervalued or unrecognized within the healthcare system, in professional decisions regarding our children, and within the communities we live in. Each diagnosed condition has its own specific attributes related to its classification, and each individual with a disability possesses unique characteristics. Understanding the unique attributes and strengths of individuals with disabilities and actively supporting these strengths, rather than focusing on their disabilities or the typical limitations associated with their diagnosed condition, can significantly enhance their ability to live the life they choose and fully participate in their communities. As a family caregiver, I understand the challenges of advocating for the unique attributes that can be fundamental to a child's life and their pursuit of individual growth and self-independence. I am also fully aware of the unique and significant sacrifices this life brings to the caregiver. As a father, I have sought to achieve a much higher level of learning and understanding regarding my child's diagnosed condition. I conducted a search of articles that explore topics related to family caregiving, recognizing the strengths of children with developmental disabilities, and the challenges caregivers face—especially regarding being heard by professionals and stereotypes about fathers. I held open discussions with self-advocates and other family caregivers to gather lived experiences and insights. Additionally, I reviewed the history and work of the Delaware Developmental Disabilities Council and related organizations. Using this information and my personal experience, I created a PowerPoint presentation that includes videos and reflections of my perspective and experiences. With this presentation, I aim to lend a voice to family caregivers, acknowledging the struggle for validation, the potential ominousness of sacrifice, and, at times, our feelings of frustration. I hope this will foster more conversations about the complexity of the developmental disability family dynamic.

CHALLENGES: A FATHER'S PERSPECTIVE AND LITERATURE FINDINGS

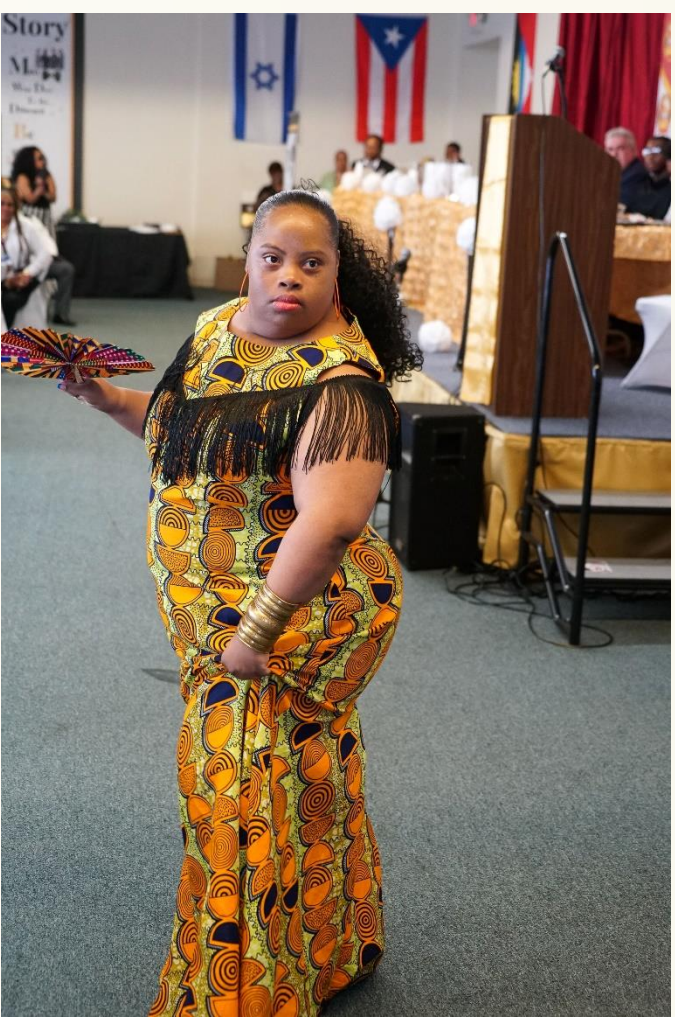
- Caregiving Demands can and some will disrupt individual life goals or plans. *Studies show "these duties can disrupt routines, careers, and personal health."* [bmcpediatr.biomedcentral.com](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10835869/)
- Sacrifice is required to learn what your child's Strengths, talents, and abilities are. *Studies show that "parents who focus on their children's strengths (talents, character, interests) foster greater resilience, optimism, behavior improvement, and mutual satisfaction in both parent and child."* [mindful.org](https://www.mindful.org/)
- Knowing these Strengths, talents, and abilities puts you in the position of expertise with regard to your child or person with the diagnosed condition. *Studies show, "Recognizing and uplifting the unique strengths and attributes of individuals with developmental disabilities rather than fixating on their labels has powerful transformative effects."* https://www.cvtcinc.com/blog/how-person-centered-services-empower-individuals-with-developmental-disabilities/?utm_source=chatgpt.com
- Having your voice heard as the expert of your Developmentally disabled child's life is challenging amongst other professionals in your child's life. *Studies show "Parents bring unparalleled knowledge: You've tracked your child's milestones, strengths, and unique challenges—all the key details educators don't see in short visits,"* [researchgate.net+3researchgate.net+3copaga.org+](https://www.researchgate.net/publication/360940040)
- In this world's fathers are many times stereotypically perceived as absent or unknowledgeable in their accountability to the welfare of their child. *This Article states, "Driven by the desire to support and protect, many dads educate themselves as part of their caregiving role."* <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC10835869/> *Study Show "Many fathers adjust work schedules, reduce hours, or become primary caregivers, sacrificing career goals and personal time."* [link.springer.com+15dsq.sds.org+15pmc.ncbi.nlm.nih.gov+15](https://www.springer.com/15dsq.sds.org+15pmc.ncbi.nlm.nih.gov+15) *Caregivers often assume roles as case managers and advocate tirelessly for quality care and inclusion.* [h2hcc.com+8mdpi.com+8teenvogue.com+8](https://www.h2hcc.com+8mdpi.com+8teenvogue.com+8)
- Education and training empower parents to better support and advocate for their loved ones. *Studies show, "Empowerment of caregivers of children with DDs and advocacy for the rights and service access for families can play a key role in developing services in an inclusive manner."* [Szlamka Z, Tekola B, Hoekstra R, Hanlon C. The role of advocacy and empowerment in shaping service development for families raising children with developmental disabilities. Health Expect. 2022;25\(4\):1882-1891. doi:10.1111/hex.13539](https://www.sciencedirect.com/science/article/pii/S0262254418821891)

COMPLEXITY OF CAREGIVING

ADVOCACY



CAREER PURSUIT



INDEPENDENCE

FOCUS THOUGHTS

- Caring for a child or adult with a developmental disability transcends mere responsibility—it is a way of life that influences every moment. While the demands of 24/7 caregiving are well-documented, the strength, insight, and profound expertise that Family caregivers bring to the table often go unrecognized.
- Emphasizing your loved one's strengths—not solely their diagnosis—fosters confidence, promotes autonomy, and enhances their quality of life. However, healthcare and education systems frequently prioritize professional credentials over lived experience. As the expert on your child or adult's needs, it is imperative that you assert your voice and ensure your insights are acknowledged in every decision-making forum.
- For parent caregivers, access to education and training is indispensable. These resources provide the knowledge, strategies, and confidence necessary to support your loved one and advocate effectively. From a father's perspective, intentional learning, emotional presence, and active advocacy are fundamental to resilient and responsive fatherhood.
- To effect meaningful change, we must initiate conversations, educate others about the complexities of caregiving, and amplify caregiver voices. By framing the caregiver experience with clarity and honesty, we cultivate empathy, raise public awareness, and advocate for systemic change. Our advocacy is crucial—in schools, hospitals, workplaces, and public policy. It is the catalyst for understanding, inclusion, and progress.

This presentation explores the experiences of parent caregivers for children and adults with developmental disabilities. It emphasizes the importance of recognizing individual strengths, validating caregiver expertise, and advocating for inclusion in healthcare, education, and policy. Through personal reflections and community dialogue, the presentation highlights the need for training, emotional presence, and systemic change, particularly from a father's perspective. For more information or to discuss presenting this work at a future event, please contact Michael Harris, MichaHar2002@yahoo.com

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- Some video footage provided by Delaware Developmental Disabilities Council: www.ddc.delaware.gov