



Caregiver Well-Being: Finding Calm in The Chaos

Shirley Ryan
Abilitylab

Presented by: Lauren Wolf, DSW and Chris Lau, LSW

Images: A serene tide pool surrounded by rocks, A Calmer Journey logo is a white circle with a blue image indicating a sun rising over the horizon above company name. The Shirley Ryan AbilityLab logo is orange font for the first three words with the word lab in red font.

Agenda

- Introduction
- Stress, Burnout, & Trauma
- What Helps You?
- Lived Experience: Caregiver Interview
- What Caregivers are Saying
- Resources & Tools
- Closing Activity

Image: A pile of rocks carefully stacked high



Your Needs Matter



We recognize that many parents also have many different roles

What other terms would you use to describe your roles?

Image: Ripples in water from an oar rowing slowly.

Understanding the Full Context of Caregiving

Caregiving does
not happen in
isolation—it
happens within
systems.

Caregiving is shaped by many
external factors

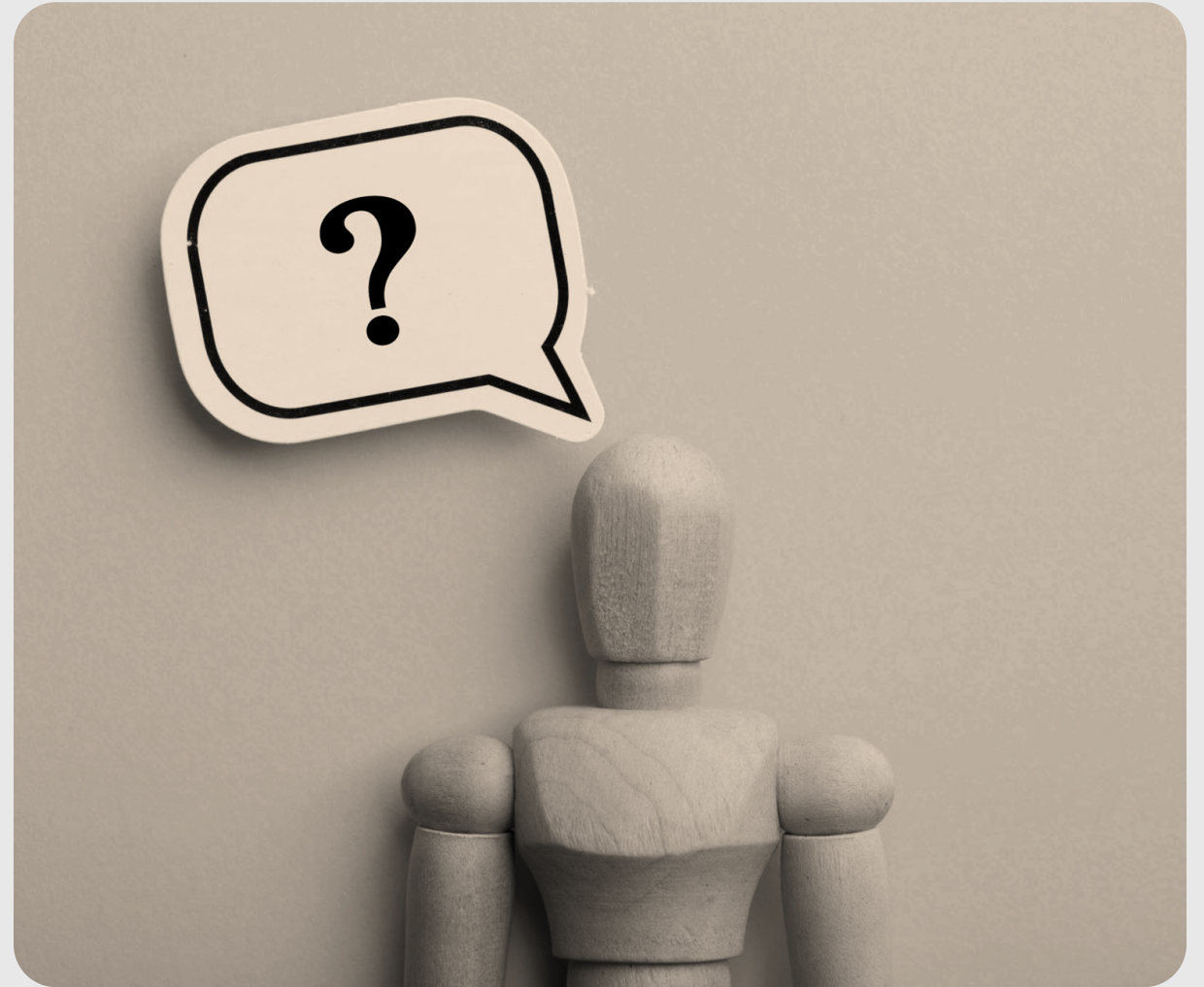
Systems, access, and
environments matter

Gaps exist in support,
resources, and services

Family well-being is deeply
interconnected

Stress and Burnout: And Why This Matters

What causes you
stress?



Why this Matters

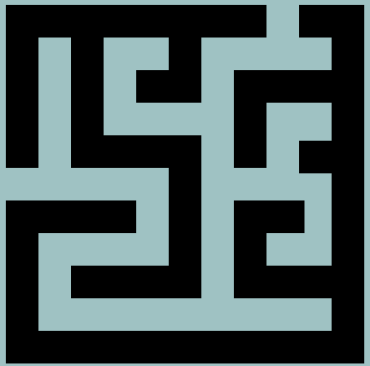


Gaps in the System Exist

Image: Puzzle pieces separated with gaps and only a few puzzle pieces connect

The Reality of Caregiving

- Medical and therapy demands
- System navigation challenges
- Financial strain
- Limited time for self-care



Images: Icons including a maze, an arrow pointing in all directions, a female figure holding an infant

What Research Shows

Higher Levels of:

- Anxiety
- Depression
- Chronic stress

Understanding Caregiver Stress

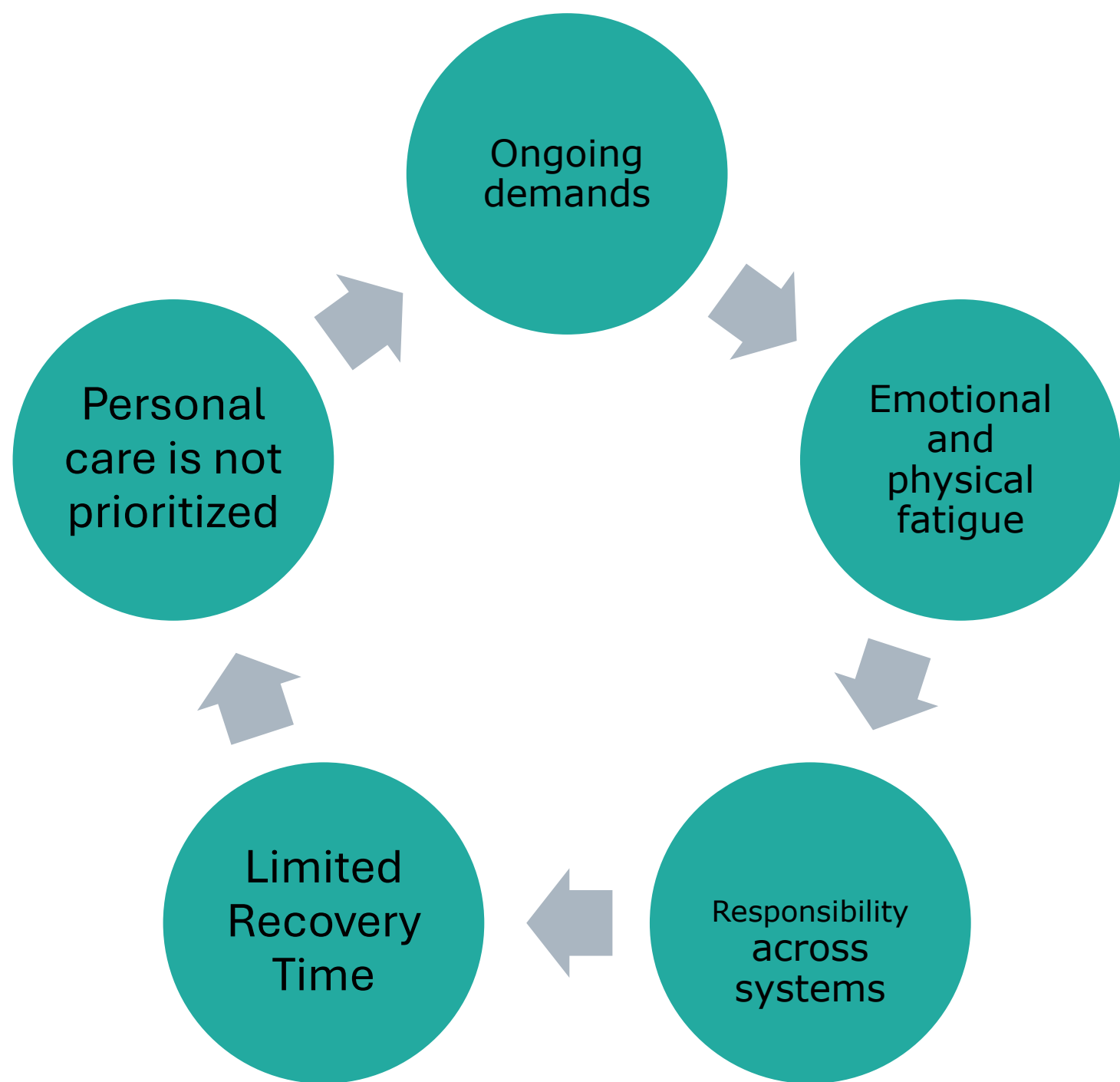


Image of circles and arrows depicting the cyclical nature of stress with the phrases: ongoing demands without pause, emotional and physical fatigue, responsibility across systems, and limited recovery time



Parental Burnout

- ✓ Emotional Exhaustion
- ✓ Feeling overwhelmed or depleted
- ✓ Difficulty sustaining demands
- ✓ No sense of a break

Risk Factors

- High caregiving intensity
- Severity of child's needs
- Limited support systems
- Structural and systemic barriers

Protective Factors

- Social support
- Access to services
- Coping skills
- Resilience-building supports

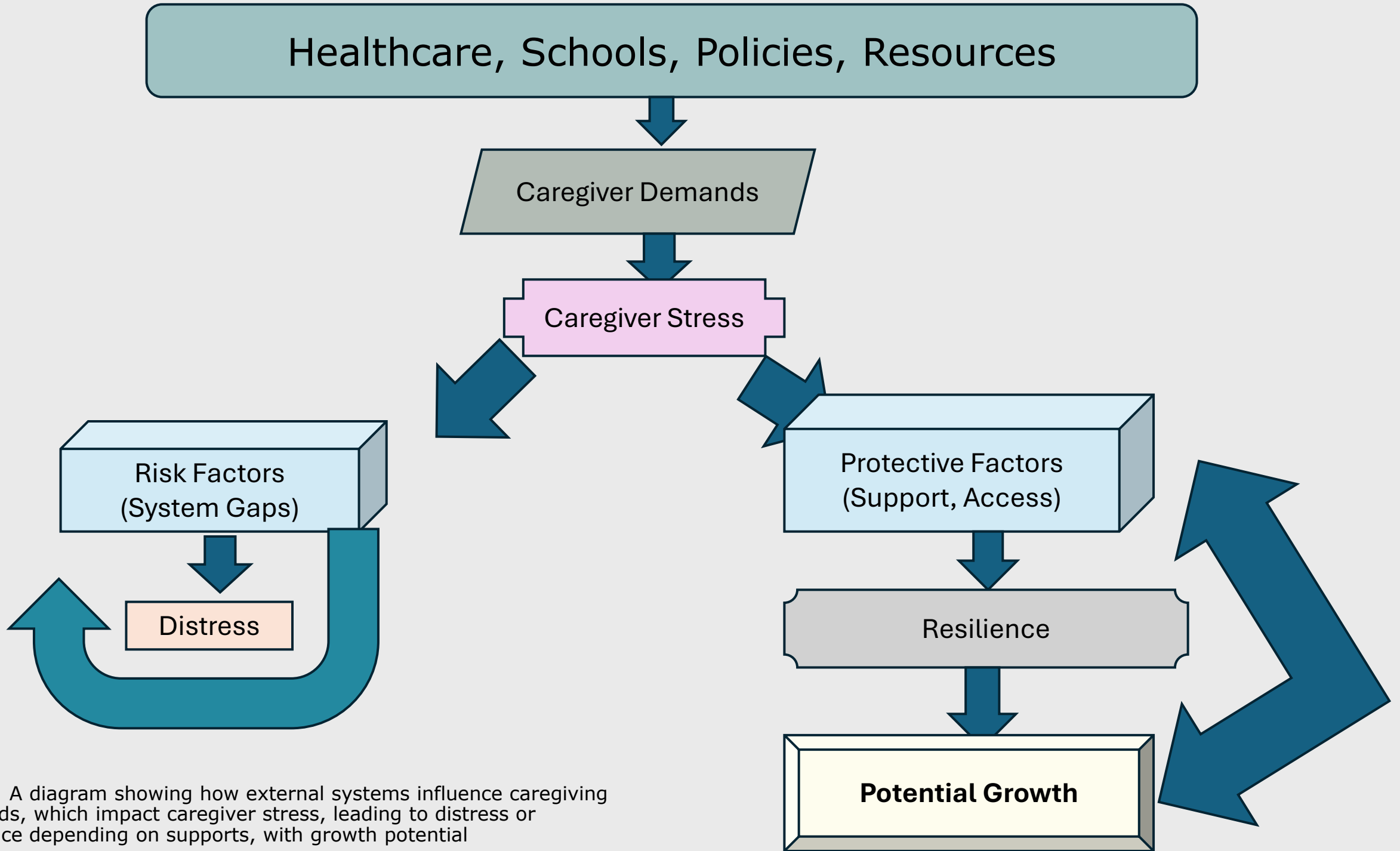


Image: A diagram showing how external systems influence caregiving demands, which impact caregiver stress, leading to distress or resilience depending on supports, with growth potential

What Caregivers Find Helpful

- Support Groups/Mentor
- Therapy
- Faith/Spirituality
- Mindfulness & Self Compassion
- Education/Advocacy



What Helps You?

Caregiver
Interview:
Liz Avila



What Caregivers Are Saying?

- "It's ok not to be ok."
- "Some days are up escalators, some are down."
- "I deserve to read a book or do yoga."
- "All I had in the beginning was faith."
- "This group helped me find my voice."

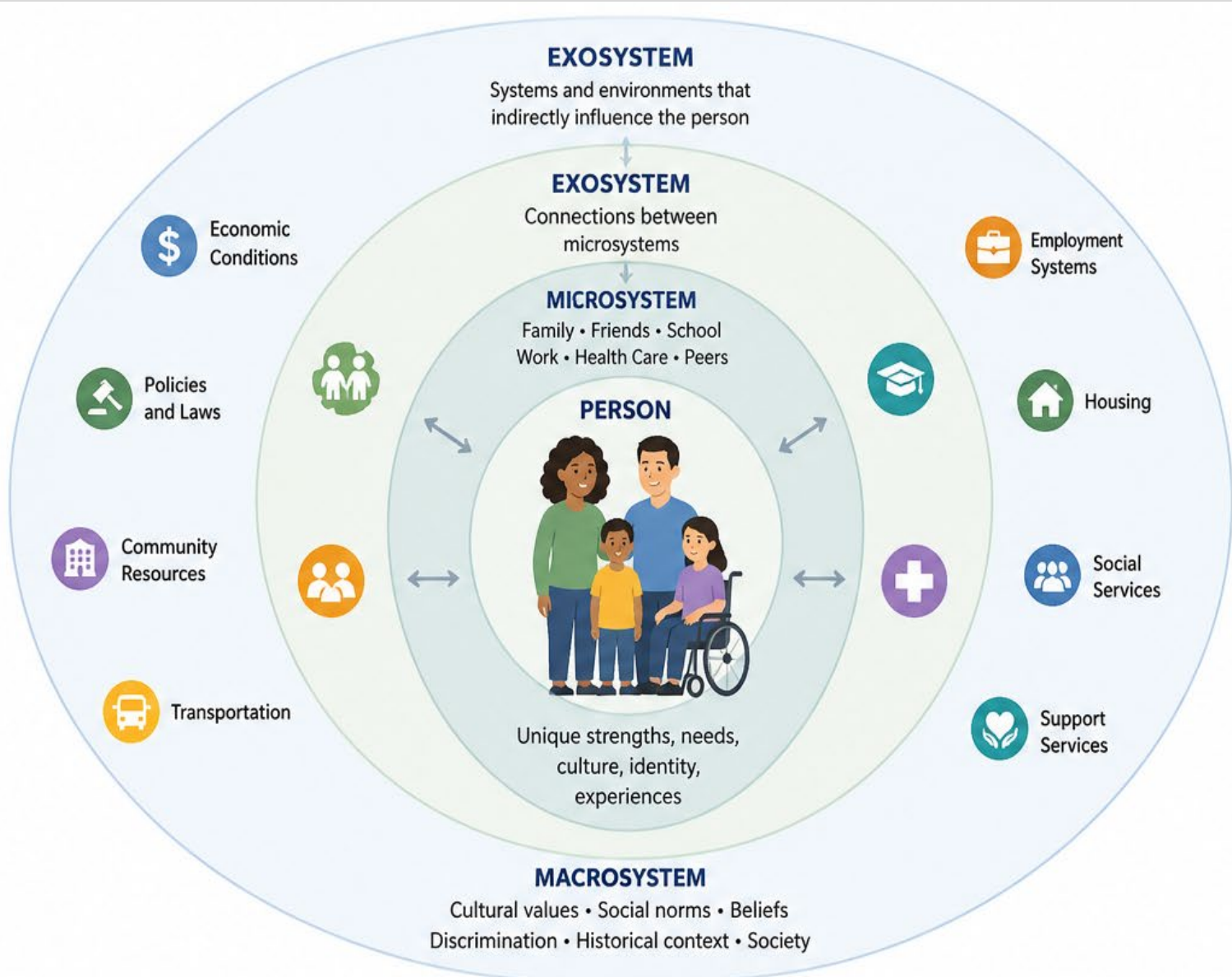
Resources and Tools

Support
Education
Advocacy
Respite
Apps

Image: A tabletop with many
different tools



Person in Environment (PIE): A Social Work Perspective



THE PERSON

At the center is the individual—with unique strengths, needs, identities, and experiences.

MICROSYSTEM

The immediate environments where the person lives, learns, works, and connects.

MESOSYSTEM

The interactions and relationships between the person's different environments.

EXOSYSTEM

Broader systems and settings that indirectly impact the person's daily life.

MACROSYSTEM


The larger cultural, societal, and historical forces that shape opportunities and challenges.

Image shows individual people in a family surrounded by circles of many environmental things that have an influence starting with family, friends, The interactions and relationships to the systems and settings people are impacted by and the larger culture and society influences including school, work, health care, peers including supports, services, Housing, employment, economy, Policies, resources, transportation

MULTIPLE SYSTEMS. CONTINUOUS INTERACTION. HOLISTIC UNDERSTANDING.

Closing Activity





Dripping water hollows out
stone, not through force
but through persistence.

Oval



Questions?

References

Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2020). Empowering self-help groups for caregivers of children with disabilities in Kilifi, Kenya: Impacts and their underlying mechanisms. *PLOS ONE*, *15*(3), e0229851.

Chen, H., Zhang, Y., & Liu, X. (2025). Resilience and affiliate stigma among parents of children with autism spectrum disorder: The mediating role of life satisfaction and the moderating role of ostracism. *Psychology Research and Behavior Management*, *18*, 1519–1529.

Cousineau, T. M., Hobbs, L. M., Arthur, K. C., & et al. (2019). The role of compassion and mindfulness in building parental resilience when caring for children with chronic conditions: A conceptual model. *Frontiers in Psychology*, *10*, 1602.

Du, X., Wang, Y., & Li, Q. (2024). The effect of social support on the mental health literacy of parents who have children with special needs: A moderated mediating effect. *Psychology Research and Behavior Management*, *17*, 1283–1294.

Findling, Y., Klein, E., & Levy, S. (2024). Parental burnout: A model of risk factors and protective resources among mothers of children with and without special needs. *European Journal of Investigation in Health, Psychology and Education*, *14*(11), 2883–2900.

Isa, S. N. I., Ishak, I., & et al. (2021). Quality of life among caregivers of children with special needs in Kelantan, Malaysia: The importance of psychosocial mediators. *Malaysian Journal of Medical Sciences*, *28*(2), 128–141.

References Continued

Kaji, N., Saito, M., & Aida, J. (2021). Children with special health care needs and mothers' anxiety and depression: Findings from the Tokyo Teen Cohort study. *Psychiatry and Clinical Neurosciences, 75*(12), 394–400.

Kuper, H., Lyra, T. M., Moreira, M. E., & et al. (2019). The association of depression, anxiety, and stress with caring for a child with congenital Zika syndrome in Brazil. *PLOS Neglected Tropical Diseases, 13*(9), e0007768.

Laufer, M., & Isman, E. (2021). Posttraumatic growth among parents of children with special needs. *Journal of Social Work in Disability & Rehabilitation.*

Lee, Y.-J., Park, H.-J., & Recchia, S. (2015). Embracing each other and growing together: Redefining the meaning of caregiving a child with disabilities. *Journal of Child and Family Studies, 24*(12), 3662–3675.

Rakap, S., & Vural-Batik, M. (2024). Mitigating the impact of family burden on psychological health in parents of children with special needs: Buffering effects of resilience and social support. *Journal of Applied Research in Intellectual Disabilities, 37*(1).

Xing, J., Wang, L., & Zhang, Y. (2025). A serial mediation model of resilience among caregivers of children with autism. *American Journal of Occupational Therapy, 79*(1), 1–8.

Thank you for listening!



Chris Lau: clau@sralab.org



<https://www.sralab.org>



Dr. Lauren Wolf: info@ACalmerJourney.com



<https://www.ACalmerJourney.com>