

The background is a dark blue gradient with a subtle pattern of small white dots. On the left side, there are several overlapping circular elements. A prominent one is a large circle with a scale around its perimeter, marked with numbers from 140 to 260 in increments of 10. Other circles are partially visible, some with dashed lines and arrows, suggesting a process or cycle. The overall aesthetic is technical and modern.

PARENTAL SUPPORT NEEDS ASSESSMENT

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PROJECT BACKGROUND

- WE FOCUS OUR EFFORTS ON OUR PEDIATRIC PATIENTS
- WHAT ABOUT THE PARENTS?
- HAVING A CHILD WITH SPECIAL HEALTHCARE NEEDS IS NO EASY TASK
- ARE WE DOING ENOUGH TO TAKE CARE OF OUR PARENTS?



FAMILY-CENTERED CARE

- Approximately 5.6 million US Children with Special Healthcare Needs (CSHCN) receive 1.5 billion hours annually of family-provided health care (Romley, Shah, Chung, Elliot, Vestal, & Shuster, 2016).
- CSHCN most likely to receive the greatest amount of family-provided health care at home were ages 0 to 5 years, were Hispanic, lived below the federal poverty level, and had no parents/guardians who had finished high school (Romley, et. al., 2016).
- Care for parents can reduce the distress of both the parental caregiver and the CSHCN (Koch & Jones, 2018).

WHY IS THIS IMPORTANT?

Attachment Theory: children need emotionally healthy caregivers in order to thrive and form secure attachments.

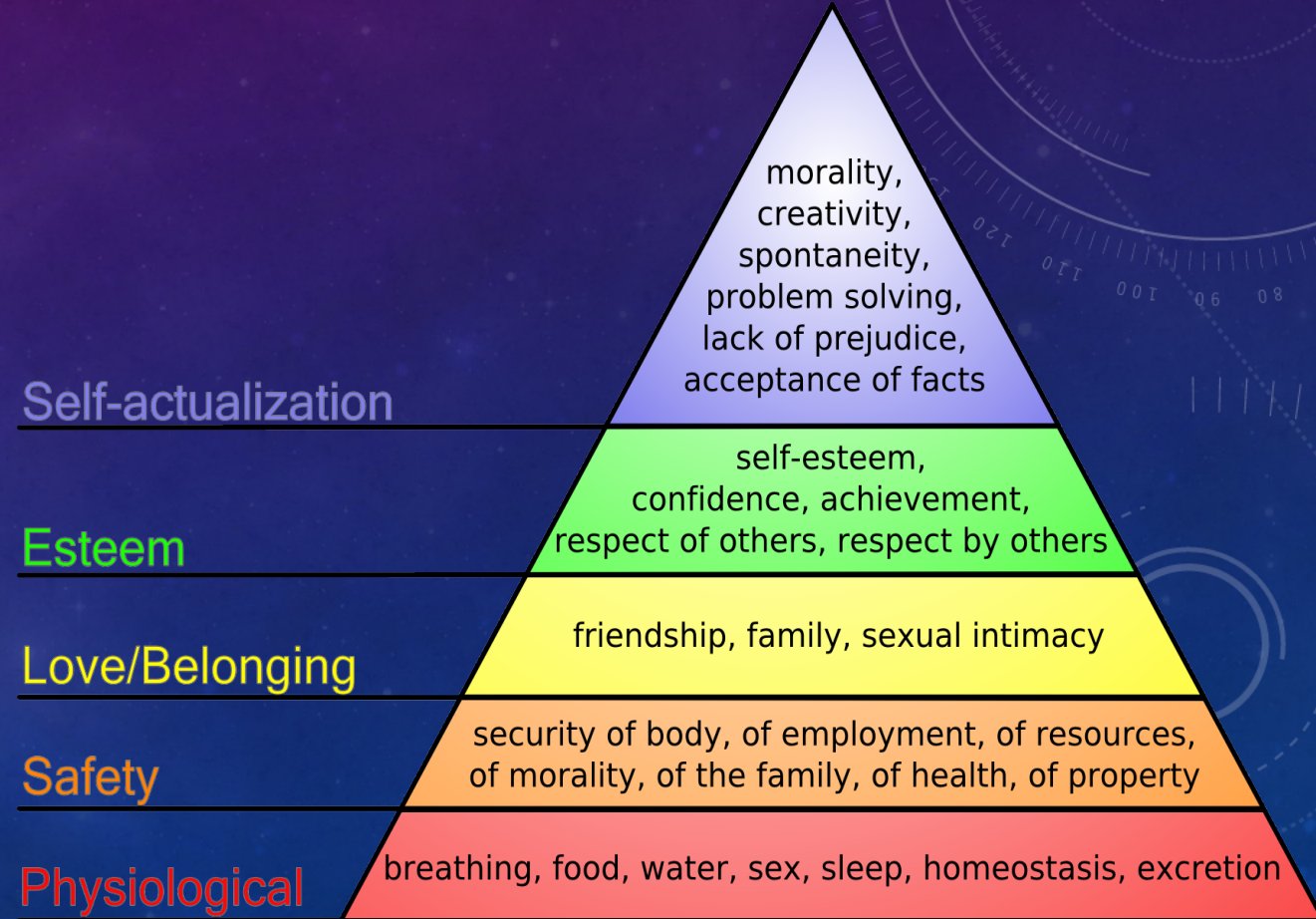
Maslow's Hierarchy of Needs and Erickson's stages of Development

ERIKSON'S STAGES OF PSYCHOSOCIAL DEVELOPMENT

Erikson's Stages of Psychosocial Development

Stage	Psychosocial Crisis/Task	What Happens at This Stage?
1	Trust vs Mistrust	If needs are dependably met, infants develop a sense of basic trust.
2	Autonomy vs Shame/Doubt	Toddlers learn to exercise will and do things for themselves, or they doubt their abilities.
3	Initiative vs Guilt	Preschoolers learn to initiate tasks and carry out plans, or they feel guilty about efforts to be independent.
4	Industry vs Inferiority	Children learn the pleasure of applying themselves to tasks, or they feel inferior.
5	Identity vs Confusion	Teenagers work at refining a sense of self by testing roles and then integrating them to form a single identity, or they become confused about who they are.
6	Intimacy vs Isolation	Young adults struggle to form close relationships and to gain the capacity for intimate love, or they feel socially isolated.
7	Generativity vs Stagnation	The middle-aged discover a sense of contributing to the world, usually through family and work, or they may feel a lack of purpose.
8	Integrity vs Despair	When reflecting on his or her life, the older adult may feel a sense of satisfaction or failure.

MASLOW'S HIERARCHY OF NEED



PROJECT IMPLEMENTATION

- FEB-APRIL: SURVEYS
 - IN CLINIC
 - EMAIL
- APRIL & MAY
 - REVIEW & NEXT STEPS

How supported do you feel by:

	Very supported	Somewhat supported	Rarely supported	Not at all supported
Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Community	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Overall, how many hours per week do you provide care for a child with CF?

- 1-25
- 26-50
- 51-100
- 100+

How many hours per week is the child or children in the care of someone other than yourself?

- 0
- 1-25
- 26-50
- 50+

Please click and drag each of the options to rank the challenges of caring for a child with CF with 1 being the most challenging and 6 being the least challenging.

Time commitment for treatments

The treatments themselves

The emotional burden of having a child with CF

When my child is in the hospital

Anxiety about the future

Other

REFERENCES

Romley, J. A., Shah, A. K., Chung, P. J., Elliot, M. N., Vestal, K. D., & Shuster, M. A. (2016). Family-Provided Health Care for Children With Special Health Care Needs. *Pediatrics*, *139*(1), 1–11. Retrieved from <https://pediatrics.aappublications.org/content/pediatrics/early/2016/12/23/peds.2016-1287.full.pdf>

Koch, K. D., & Jones, B. L. (2018). Supporting Parent Caregivers of Children with Life-Limiting Illness. *Children (Basel, Switzerland)*, *5*(7), 85. <https://doi.org/10.3390/children5070085>

The background is a dark blue gradient with a subtle pattern of small white dots, resembling a starry sky. Overlaid on this are several faint, light blue technical diagrams. These include circular gauges with numerical scales (e.g., 100, 110, 120, 130, 140, 150, 160, 170, 180, 190, 200, 210) and arrows, as well as dashed lines and concentric circles, suggesting a scientific or engineering theme.

THANK YOU!