SUPPORTING THE FINANCIAL AND RELATIONAL LIVES OF FAMILIES WITH DISABILITIES

UNIVERSITY OF GEORGIA
College of Family and Consumer Sciences
Love and Money Center
David Ralston Institute for Behavioral Health and Developmental Disabilities

ABILITY WEALTH GROUP

1

WELCOME

- Marketing release
- CE instructions
  - Step 1: Sign in now
  - Step 2: At the end, fill out the form (in packet, also a QR code)
- Welcome to Tate!
  - Starbucks is upstairs
  - Restrooms are on same level
  - Chick-Fil-A lunch will be at noon
- If you have a problem, see our interns

Sign the marketing release on paper – OR – use this QR code to fill it out online

2

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Step 1: Sign in at the registration table for CE credits

Or use this QR code

3

WELCOME

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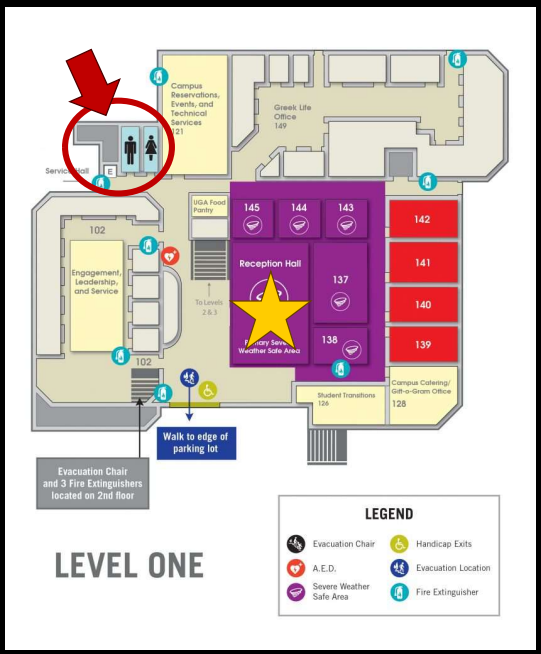

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PRESENTERS

Christine Hargrove, PhD, LMFT, CFT™
Clinical Assistant Professor & Assistant Director of the Love and Money Center
UGA FACS

Carol Britton Laws, PhD, MSW, FAAIDD
Clinical Professor & Director of Instruction, Ralston Institute
UGA FACS

Jason Norton, CFP®, ChSNC®
Founder, Ability Wealth Group
UGA FACS Alumnus

Doug Crandell, MFA
Project Director of Advancing Employment, Ralston Institute, UGA FACS

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WHY THIS WORKSHOP EXISTS

...and why it matters

7

OUR WORK TOGETHER TODAY

Share knowledge across disciplines

Pique your interest

Encourage collaboration

Identify future opportunities

8

AGENDA

Context and Systems: Understanding the World Families Navigate

- How family needs, stressors, and priorities shift from early childhood through adulthood
- The layered systems surrounding families and why context shapes everything

Research, Frameworks, and What Helping Professionals Need to Know

- Research on common experiences and patterns
- A framework for understanding your role in helping

Financial Planning for Families with Disabilities

- Why having a family capacity perspective matters
- Financial and legal considerations
- Government benefit programs

Moderated Lived Experience Panel

9

For the next three hours, turn off the idea that "this does not apply" to you.

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CONTEXT AND SYSTEMS: UNDERSTANDING THE WORLD FAMILIES NAVIGATE

Carol Britton Laws, PhD

Clinical Professor, Director of Instruction

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College of Family and Consumer Sciences
Love and Money Center
David Ralston Institute for Behavioral Health and Developmental Disabilities

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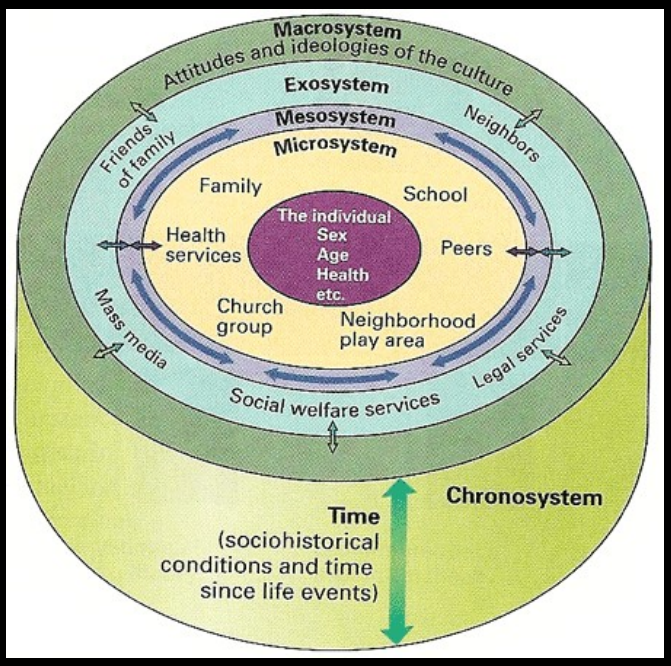
BROFENBRENNER'S ECOLOGICAL SYSTEMS MODEL



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DEVELOPMENTAL DISABILITIES

According to the DD Act (adopted in 2000), a developmental disability:

"(i) is attributable to a mental or physical impairment or combination of mental and physical impairments;

(ii) is manifested before the individual attains age 22;

(iii) is likely to continue indefinitely;

(iv) results in substantial functional limitations in 3 or more of the following areas of major life activity:

(I) Self-care.

(II) Receptive and expressive language.

(III) Learning.

(IV) Mobility.

(V) Self-direction.

(VI) Capacity for independent living.

(VII) Economic self-sufficiency; and

(v) reflects the individual's need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated."

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HOW DIAGNOSIS IS GIVEN TO FAMILIES

Prenatally by physician
- Genetic testing

Postnatally by physician
- APGAR scores, developmental milestones

Throughout childhood development by physician
- Pediatrics

Throughout childhood development by psychologist
- School counselors/teachers

After developmental years by psychologist or physician
- Medical and/or psychosocial evaluation

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DIAGNOSIS IN EARLY CHILDHOOD

The diagnosis is the first step to be considered in the management of these cases and access to resources. A sensitive approach must be taken by a senior professional.

- The family's initial reaction may be similar to one of bereavement:
  - Shock and confusion
  - Fear
  - Loss
  - Anger
  - Guilt
- Families will also suddenly have to face making important decisions during the different stages of their child's disability.

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FACTORS THAT AFFECT CHILD DEVELOPMENT

Poverty highly correlated to disability

- Increased likelihood of having a child with a disability
  - Poor health, restricted diet, toxins and environmental pollutants
  - Risk increased for poor sanitation, exposure to illness, lack of access to health care, inadequate housing, neglect and abuse, increased maternal stress, inadequate stimulation, violence
- Consequence of having a child with disability
  - Economic and social disadvantage. Higher costs, missed work, siblings taken out of school to care, transportation limitations/expenses, health care costs

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WHO ARE OUR CAREGIVERS?

- Unpaid – Approximately 59 million family caregivers have provided unpaid care to an adult or child in the last 12 months.
- Upwards of 75% of all caregivers are female and may spend as much as 50% more time providing care.
- Of family caregivers who provide complex chronic care:
  - 46% perform medical and nursing tasks;
  - More than 96% provide help with activities of daily living (ADLs) such as personal hygiene, dressing and undressing, getting in and out of bed, or instrumental activities of daily living (IADLs) such as taking prescribed medications, shopping for groceries, transportation, or using technology, or both.
- Those caring for a child under age 18 spend 29.7 hours per week performing caregiving tasks.

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EXCEPTIONAL CAREGIVING

EXCEPTIONAL CAREGIVING RESPONSIBILITIES[14]
(ROUNDTREE & LYNCH, 2006)

Caring for a child/youth with typical development	Caring for a child/youth with special needs/disabilities
Constant care that diminishes	Constant care that often escalates
Ordinary input of time and energy	Extraordinary input of time and energy
Easier as time goes by	Often harder as time goes by
Few interruptions are emergency-driven	Many interruptions are emergency-driven
Child/youth grows increasingly independent	Child/youth may grow increasingly dependent
Requires some lifestyle adjustments	Requires numerous lifestyle adjustments
Challenges and successes are easily shared	Challenges are rarely shared; successes are fewer

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DISABILITY ISSUES IN CHILDHOOD AND ADOLESCENCE

Caregiver Strain & Burnout

- Lack of extended family support
- Difficult work-life integration

Cost and Availability of Therapy

- Clinical interventions offered by school system
- Appointments only during daytime hours on weekdays
- Health Insurance coverage / Medicaid

Navigating Systems

- Educational, Medical, Employment, Residential

Planning for the Future

- Sibling engagement
- Financial planning

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DISABILITY ISSUES IN ADULTHOOD

Transition from Educational System to Adult Life (22+)

- Postsecondary education – IHE's & IPSE
- Vocational education -GVRA
- Integrated employment (including supported employment) - GVRA
- Adult services -DBHDD
- Independent living- CILs
- Community participation

Medicaid and Waiver Services

- Residential and employment supports
- Health insurance, durable medical equipment

SSI/SSDI – Social Security Benefits

- Benefits navigators

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DISABILITY ISSUES IN ADULTHOOD

Accessible and Affordable Housing

- Section 8 – Housing Choice Voucher Program – HUD
- 2.4 million households with nonelderly people with disabilities, including 1 million families with children, have "worst-case" housing needs
  - Unassisted very low-income renters who either (1) pay more than one-half of their monthly income for rent; or (2) live in severely inadequate conditions, or both. Nearly 40 percent of all worst-case housing needs in the United States.

Marriage and Parenthood

- Resource Penalties, Disproportionate child removal rates

Employment

- Unemployment/underemployment high – often double those without
- Retirement uncertain – 401k and financial planning unavailable

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RESOURCES: PARENT TO PARENT OF GA- HTTPS://WWW.P2PGA.ORG/

CORE SERVICES

- Special Needs Database
- Navigator Projects
- Supporting Parents
- One on One Assistance
- Roadmap to Success
- Trainings
- Unique Online Opportunities

P2P provides services to people with any disability. P2P also provides services in Spanish and other languages.

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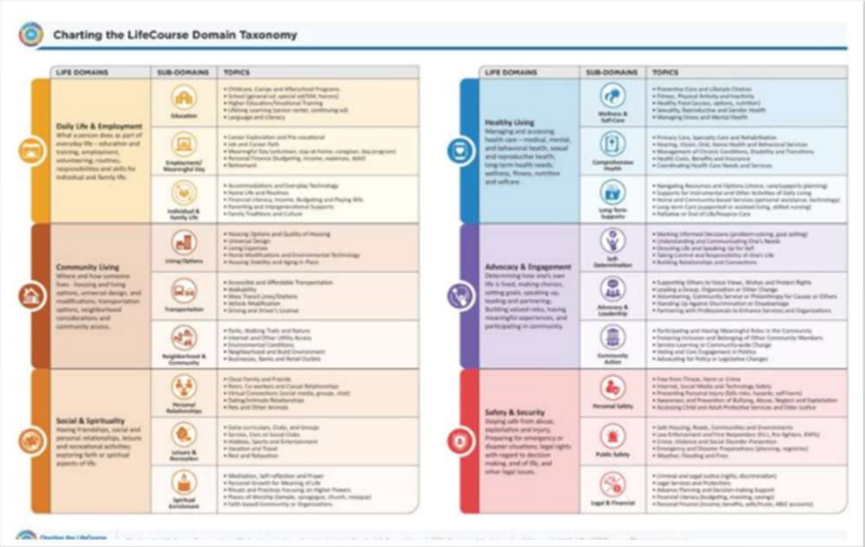
RESOURCES: CHARTING THE LIFECOURSE

The Charting the LifeCourse framework was created to help individuals and families of all abilities and all ages develop a vision for a good life, think about what they need to know and do, identify how to find or develop supports, and discover what it takes to live the lives they want to live.



https://www.lifecoursetools.com/lifecourse-library/lifecourse-framework/

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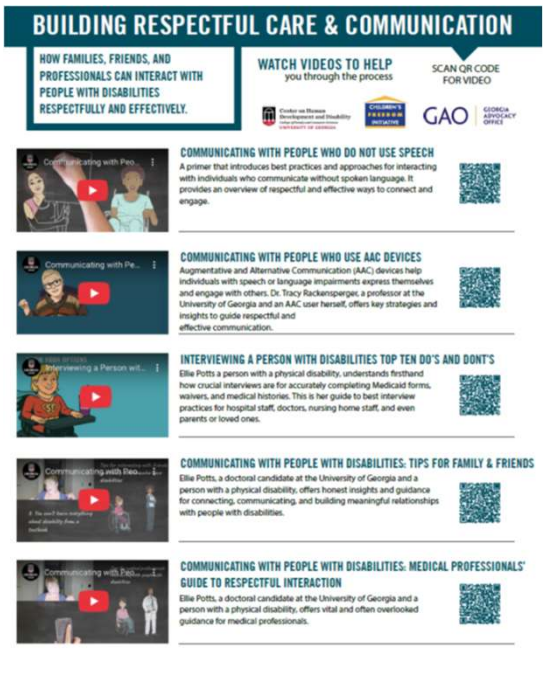
RESOURCES: NO PLACE LIKE HOME: A GUIDE TO DISABILITY, CARE, AND COMMUNITY

- Understanding disability, breaking myths, and empowering families to choose home and community life over institutional care
- Three-part video series
  - Defining Disability and Choosing Home
  - Navigating Medicaid and PASSR
  - Building Respectful Care and Communication



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RESEARCH, FRAMEWORKS, AND WHAT HELPING PROFESSIONALS NEED TO KNOW

Christine Hargrove, PhD, LMFT, CFT™

Clinical Assistant Professor & Assistant Director of the Love and Money Center

UNIVERSITY OF GEORGIA

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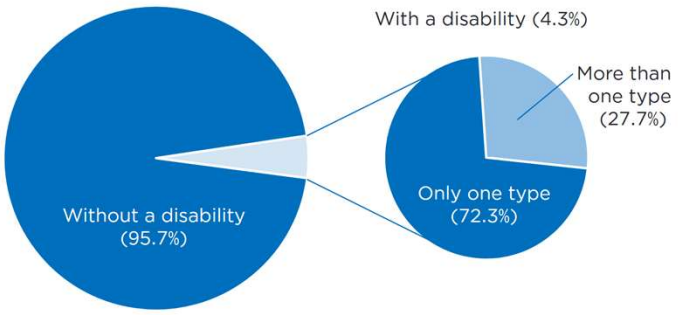
HOW MANY FAMILIES ARE WE TALKING ABOUT?

7.2 percent (2.6 million) of U.S. households with children (<18) have at least one child with a disability

About ¼ of children with a disability have more than one type of disability (U.S. Census Bureau data; Young, 2021)

Rates of childhood disability increased from 2009 – 2017 (Zablotsky et al., 2019)

Figure 1.
Percentage of Children Under the Age of 18 With a Disability: 2019



Note: Data based on sample. For information on confidentiality protection, sampling error, nonsampling error, and definitions, see <www.census.gov/programs-surveys/acs/technical-documentation/code-lists.html>.
Source: U.S. Census Bureau, 2019 American Community Survey, 1-year estimates.

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MENTAL HEALTH

- Higher parenting stress (especially mothers; Cheng & Lai, 2023)
- Anxiety symptoms (e.g., excessive worry)
- Depressive symptoms (e.g., sadness, hopelessness, low mood)
  - Suicidal ideation
- Cognitive issues (e.g., forgetfulness, brain fog)
- Guilt, self-blame for child's condition
- Anticipatory grief
- Mood swings (Shahali et al., 2024)
- Emotion regulation among parents of children with disabilities may be compromised by
  - Intensified negative emotions
  - Depleted cognitive resources
  - Challenging parent-child interactions (Strained Parenting and Emotion Regulation (SPER) model; Keleynikov, 2023)

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PHYSICAL HEALTH

- Constant physical fatigue
- Migraines
- Hypertension & high blood pressure
- Diabetes
- Nutrition difficulties
- Physical abuse & self-harm (Shahali et al., 2024)

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SOCIAL EXCLUSION

- Social isolation (Cheng & Lai, 2023)
- Stigma
- Discrimination
- Desire to prove others wrong about living with disability
- Desire for cohesion with support networks
- Strong need for support from communities and helping professionals (Shahali et al., 2024)

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FINANCIAL RISKS

- Higher rate of poverty (Young, 2021)
- Higher healthcare costs
- Long-term debt accumulation (Houle & Berger, 2017)
- Lower productivity
  - Many families have to have at least one adult (typically a mother) reduce their workload to become the primary caregiver (Houle & Berger, 2017; Shahat & Greco, 2021)

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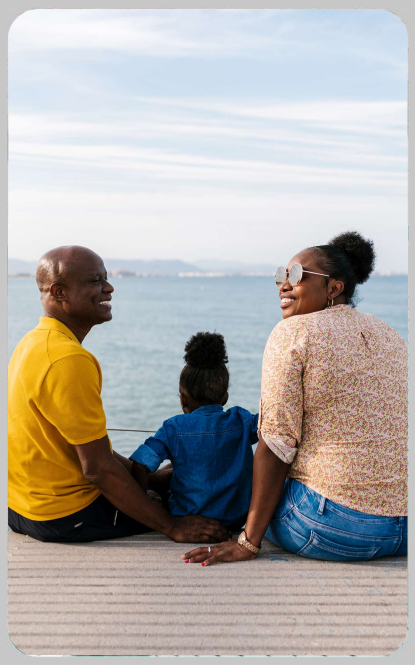
Couple Relationships

- Raising a child with a disability can negatively impact couples
  - Varies by disorder and type of symptoms/behavior (especially invisible disorders or stigmatized behaviors; Green et al., 2016)
- Dyadic coping
  - Common
  - Supportive
  - Delegated
  - Ambivalent
  - Hostile (Bodenmann, 1997)
- Effects of partners' coping styles ripple outward
  - Mothers tend to feel less stressed when they feel their partner is a supportive coparent (Song et al., 2015)
  - Partners feel more satisfied with their relationship when they engage in positive dyadic coping (Vrankić Pavon et al., 2024)
- Coping with financial stress is tricky
  - Asking for help with finances or acting stressed out tends to lead to hostile coping (Falconier, 2019)



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SINGLE PARENTING

- Raising a child/children alone due to separation, divorce, death of partner
- Single parenting (vs. two-parent household parenting) compounds the issues discussed earlier
  - Finances (Lindsay et al., 2025b)
  - Mental health (Kim et al., 2023)
  - Physical health (sleep!)
- Loneliness (Royke Tony Kalalo, 2024)
- Resilience a particular need (Antari & Susilawati, 2025)

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SIBLINGS

- Current, affected family members
- Future caregivers
- Positive aspects – shared family identity, increased compassion
- Parental coping strategies directly predict sibling quality of life
  - Parentification can negatively impact sibling relationship
  - Siblings may "protect" parents from their own negative feelings
  - Siblings both understand situation and have conflicted emotions, struggle to talk about it (Múries-Cantán et al., 2023)
- Preparation programs can be a protective intervention (Nguyen, 2023)

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GRANDPARENTS

Even if not primary caregivers, grandparents can be a major source of support

- Emotional support
- Instrumental/task support
- Family mediator
- Advocate
- Roles change over time

Grandparents have their own concerns as well

- May need time to adjust
- Often worry about their children's well-being ("double grief and worry")
- Make choices that sacrifice their own well-being
- Very little support/community connection available to them (Novak-Pavlic, 2022)

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RACE, LOCATION, & MORE

- Experiences of family disability vary across contexts
- Rural families
  - Lower access to knowledgeable care & resources
  - Travel and transportation challenges
  - Exacerbated risks to emotional & social well-being
  - Some experiences of increased sense of community/social support (Lindsay et al., 2025a)
- Racial minority families
  - Face greater risk of poverty (Lindsay et al., 2025b)
  - Experience lower educational attainment (Lindsay et al., 2022)

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FAMILY VIOLENCE/ABUSE

- People with disabilities are at elevated risk for violence/abuse within the home
  - Physical
  - Emotional
  - Financial
- Caregiving relationships can create conditions for abuse
- Interventions
  - Raise awareness & reduce stigma
  - Screening programs
  - Direct programs and services (Saleme, 2023)

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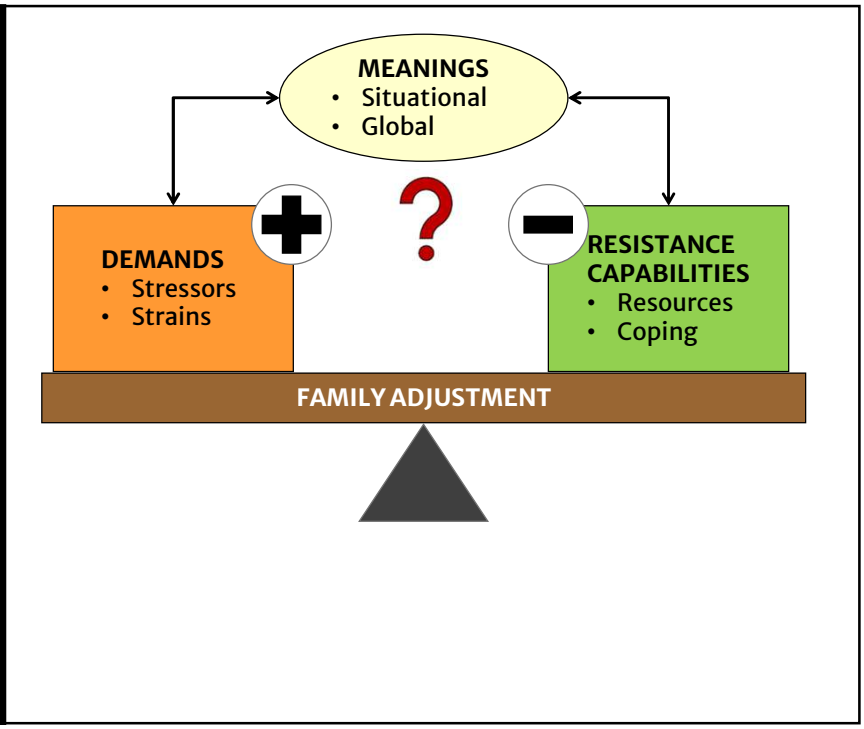
Understanding Imbalance and Your Role in Helping

Family Adjustment and Adaptation Response (FAAR) Model (Patterson, 1988)



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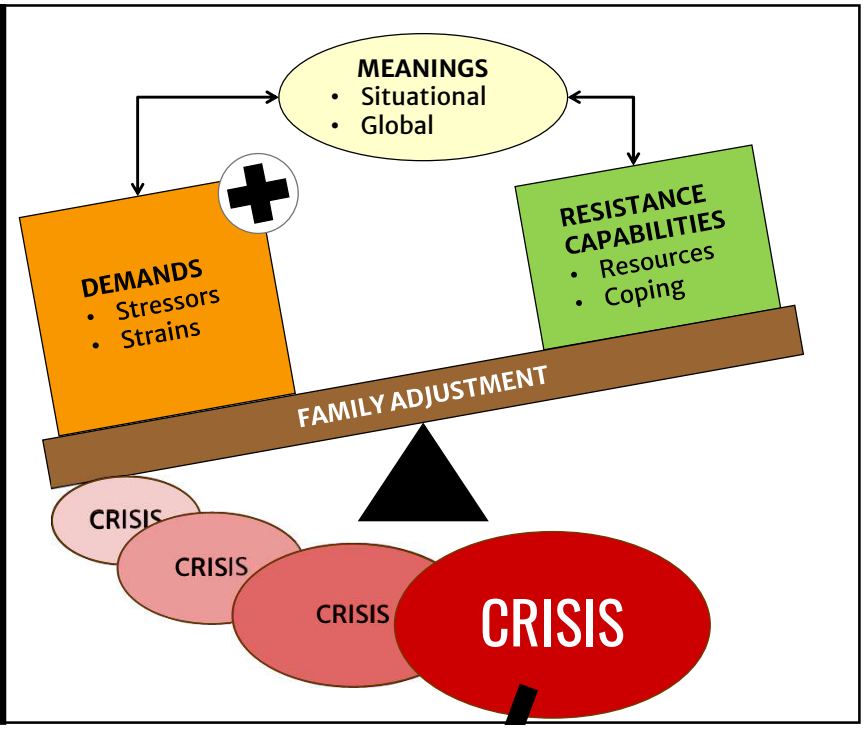
ADJUSTMENT PHASE



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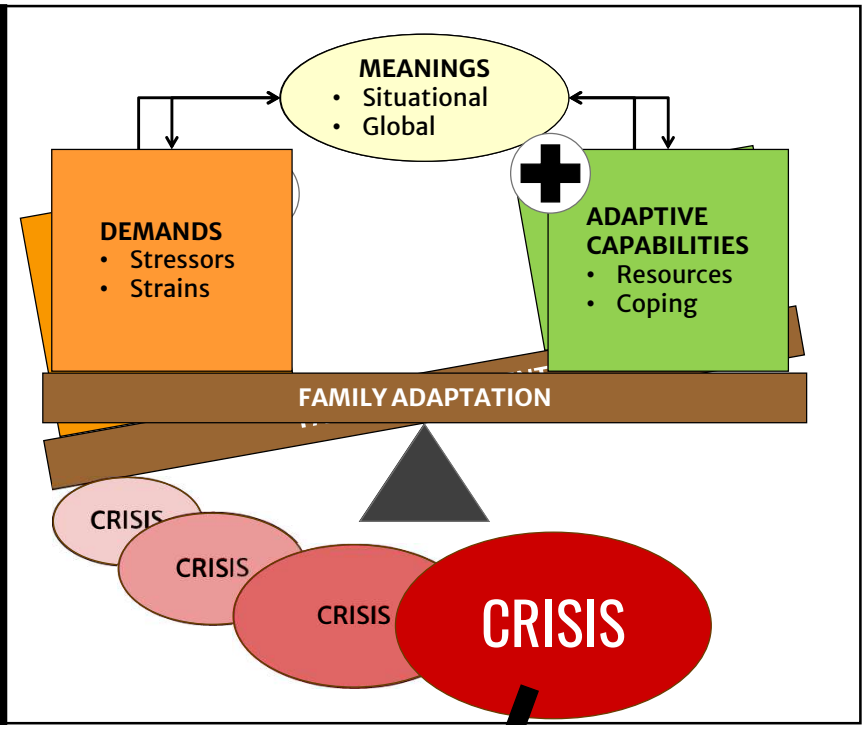

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SHORT BREAK

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UNDERSTANDING CAPACITY

WHAT HAPPENS WHEN WE LEAVE TOO MANY APPS AND TABS OPEN?

- **Limits computing power of the phone**
- **Drains the battery**

HOW THIS TRANSLATES OVER TO OUR FAMILIES:

- **An app left open equates an action families have on a to do list**
- **Capacity gets maxed out; families' batteries get drained**
- **Leading to a prioritization of actions, thus some get delayed**

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THE

ELEMENTAL CHART OF A SPECIAL NEEDS FAMILY

1 Uk Unknown																	2 F Faith
3 Di Diagnosis	4 Hc Health Care	5 Gu Guilt									6 V3 VVV	7 Fam Family	8 Tp Trusted Profs	9 Vi Village			
10 St Stress	11 T Time	12 Wa Waivers	13 Gr Grief	14 Cgv Care Givers		15 A Advocacy	16 O Organize	17 Dp Define Priority	18 N Network	19 P Patience							
20 Pt Therapy	21 S Schedule	22 Dr Physicians	23 Ss SSI	24 Ep Employment	25 Sc School	26 Snt 1st or 3rd	27 G Guardian	28 Fp Financial Plan									
29 Ot Therapy	30 Sp Therapy	31 Sd SSDI	32 Sb Siblings	33 Cc Cost of Care	34 Pr Parent Rights	35 Ct Corp Trustee	36 L Legal										
37 Kb Katie Beckett	38 M Mobility	39 Hi Health Ins	40 Cg Care Giving	41 Mcd Medicaid	42 Mr.s Marriage												
43 Pc Plan of Care	44 Me Mobility	45 D Divorce	46 IEP Ed. Plan	47 Ru Daily Average	48 Ret Retirement												

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Supplemental Needs Trusts

The One Who Needs the Money the Most Can't Have It

- There is a common misconception that trusts are for high income families
- Protect benefit eligibility by preventing assets from being counted towards limits
- Funds can be used for extra needs that are not covered by Medicaid or SSI
- There are two different types of SNTs varying in significant ways

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Supplemental Needs Trusts

Two Types : First & Third Party SNTs

First Party SNTs	Third Party SNTs
Funded with assets belonging to the beneficiary	Assets funded by family members
Reimbursement to Medicaid upon beneficiaries' death	No Reimbursement to Medicaid

45

ABLE Accounts

Eligibility age and allowed contribution amount changed this year

- Asset limit
- State Sponsored
- Used for Qualified Disability Expenses
- Allows individuals to save money without jeopardizing their benefit eligibility
- Easy to Open & Administer

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It's Complicated

Not just a Facebook relationship status..

- SNT In-Kind Support and Maintenance (ISM)
- Asset limits and Deeming Waivers
- ABLE Account size limits
- Working while receiving benefits

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Things to consider when planning for siblings

LOCATION	TIME	OWN PERSONAL COMMITMENTS	BOUNDARIES
Considering where they are located and how it will impact transitions and routines in their loved one's life	Acknowledging the time that is invested into their sibling	Understanding their other responsibilities and commitments in their personal lives	What a sibling can do to support their loved one while respecting the boundaries they have in place

SIBLINGS = SUSTAINABILITY

(SOMETIMES)

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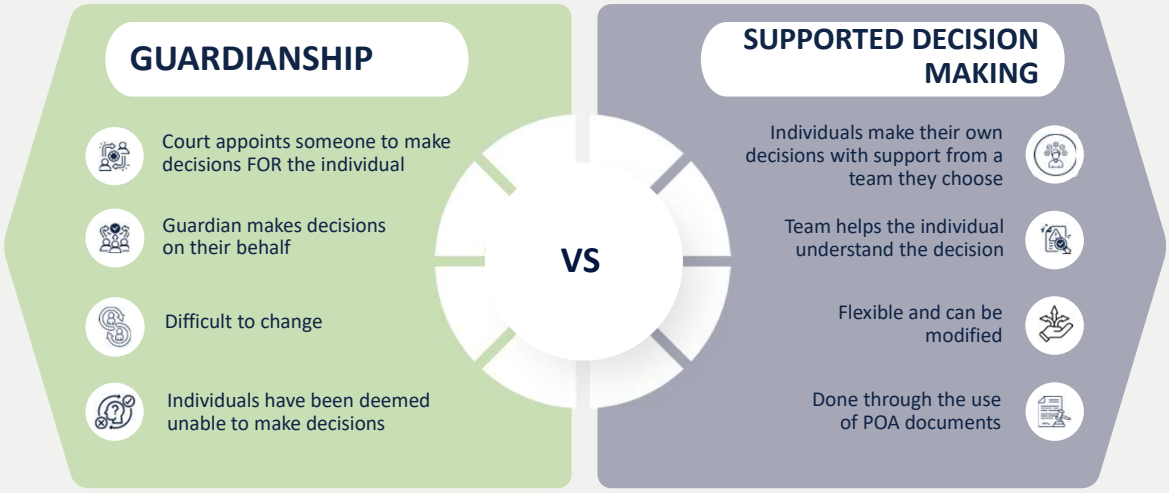
How do siblings advocate?



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Thank you very much!

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DISABILITY BENEFITS 101 – DOUG CRANDELL

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SUPER-SHORT BREAK

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WELCOME PANELISTS

- Dr. Tracy Rackensperger –Public Service Faculty, Center on Human Development and Disability
- Doug Crandell – Public Service Faculty, Center on Human Development and Disability
- Zoila and Marina Martinez – 2021 Destination Dawgs at UGA graduate and parent
- Parisha Farin Rahman – UGA Disability Ambassador

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What do you wish the professionals in your life had understood about your family's experience?

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Where have financial or mental health professionals gotten it right — or missed the mark?

55

What resources have made the biggest difference, and how did you find them?

56

What would have helped earlier in the journey?

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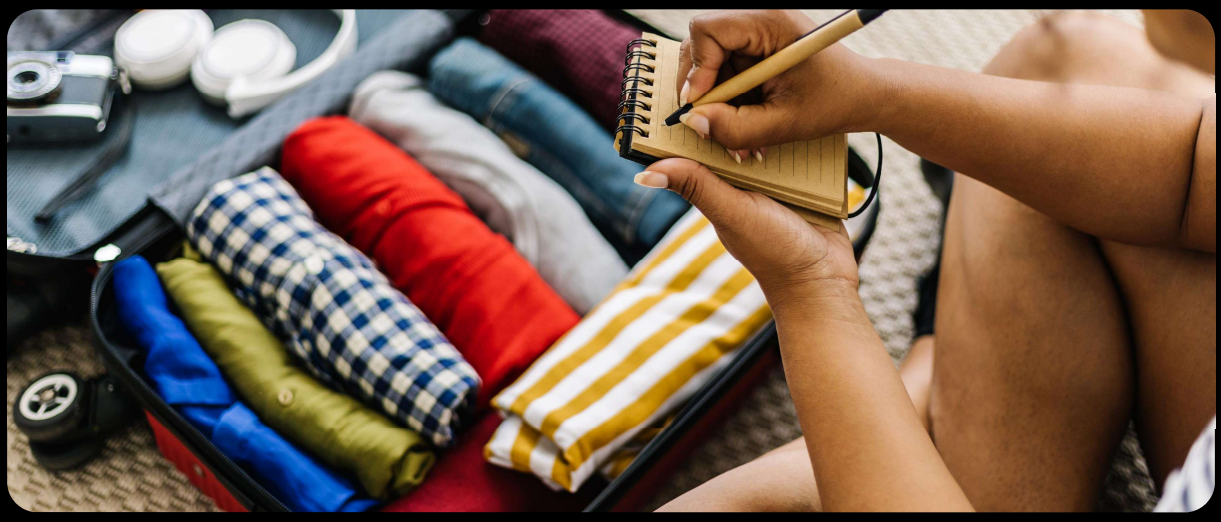

KEY TAKEAWAYS

What we will take with us from today's presentation

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THANK YOU

- Review of resources
- Lunch instructions
- We will stay for questions
- Resources handouts

Contact Us

- Christine Hargrove: christine.hargrove@uga.edu
- Carol Britton Laws: cblaws@uga.edu
- Jason Norton: jason@abilitywealthgroup.com

Please fill out the final survey!
(also available in your folder)

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