NAVIGATING THE MAZE: MAPPING SUPPORTS FOR YOUR LIFE COURSE

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ABOUT ME

- Sibling of 30 year old brother with developmental disability
- Director Individual Advocacy & Family Support
  UMKC Institute for Human Development
  - 12 years supporting self-advocacy movement (People First of MO and SABE)
  - Director of Mo Family-to-Family
  - Technical assistance to continue moving policy and practices to support the “national agenda for supporting families with disabilities”
MY FAMILY
GOALS OF PRESENTATION

- Become familiar with the formal system of supports in Missouri
- Learn about informal supports and why they are crucial for families
- Discover how to make the transitions from one system to another as seamless as possible
# Charting a New Reality

<table>
<thead>
<tr>
<th>Charted Traditional or familiar</th>
<th>Slightly Charted Tried but not norm</th>
<th>Uncharted New or unfamiliar</th>
<th>Unknown Not yet discovered</th>
</tr>
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</table>

- Removes value judgments and blame
- Not a continuum, but current or historical options
- Does not imply it is or isn’t available
- Allows for comparison of where you are and where to go
Why Uncharted Waters?

- **Journey:** Recognizing life is not static
- **Exploring:** Identifying new options and possibilities
- **Navigating together:** Sharing responsibility
- **Our overall compass is** “quality of life”
WHERE WE ARE GOING

Where we have been...
REAL LIVES, REAL PEOPLE...
UNCHARTED LIVES
UNCHARTED LIFE COURSE

Healthy & Happy
Friends & Family
Financial Stability
WHAT WE KNOW:
CHARTED DISABILITY SERVICES

Community

Family

Disability Services

Person with Disability
UNKNOWN VISION FOR THE FUTURE
WHAT WE WANT:
SERVICES TO SUPPORT REAL LIVES

Community

Family

Person with Disability
VISION FOR A FUTURE

Services
Supports
Financing

Healthy & Happy
Friends & Family
Meaningful Activity
FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE

For Families with Members with Disabilities
SUPPORTS TO MAKE THIS POSSIBLE

*Families:*
will be supported in ways that maximizes their capacity, strengths and unique abilities
so they can best support, nurture, love and facilitate......

Individual with Disability:
achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life

Birth——Early Child——School——Transition——Adulthood——Aging

*National Definition for “Supporting Families” (2011 Wingspread)*
OPPORTUNITY FOR SELF-DETERMINED AND UNCHARTED LIFE

Developmental Disability Assistance and Bill of Rights Act, 2000

- Enjoy the opportunity to live independently,
- Enjoy self-determination,
- Make choices,
- Contribute to society
- Experience full integration and inclusion in the economic, political, social, cultural, and educational, mainstream of American Society.
# FAMILY ROLES ACROSS LIFECOURSE

<table>
<thead>
<tr>
<th>Caring About</th>
<th>Caring For</th>
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</thead>
<tbody>
<tr>
<td><strong>Affection &amp; Self-Esteem</strong></td>
<td>Facilitator of inclusion, recreation, spirituality &amp; meaningful activities</td>
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<tr>
<td>Repository of knowledge</td>
<td>Advocate for support</td>
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<tr>
<td>Lifetime commitment</td>
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<tr>
<td>Provider of day-to-day care</td>
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<td>Material/Financial</td>
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CHARTER FOR SUPPORTS

DISCOVERY AND NAVIGATION
Information and Training Supports

PEER SUPPORT NETWORKS
Emotional Supports

DAY-TO-DAY NEEDS
Services for Daily Needs
### Information and Training Supports: Knowledge and Skills

- Information on disability
- Knowledge about best practices and values
- Skills to navigate and access services
- Ability to advocate for services and policy change

### Emotional Supports: Mental Health and Self-efficacy

### Day-to-Day Supports: Services for Daily Needs

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**SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFECOURSE**
<table>
<thead>
<tr>
<th>Information and Training Supports: Knowledge and Skills</th>
<th>Emotional Supports: Mental Health and Self-efficacy</th>
<th>Day-to-Day Supports: Services for Daily Needs</th>
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<tbody>
<tr>
<td>• Parent-to-Parent Support</td>
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<td>• Self-Advocacy Organizations</td>
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<td>• Family Organizations</td>
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<td>• Sib-shops</td>
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<td>• Support Groups</td>
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<td>• Professional Counseling</td>
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<td>• Non-disability community support</td>
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SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFE COURSE

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<tr>
<td>• Self/Family-Directed services</td>
<td>• Transportation</td>
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<td>• Respite/Childcare</td>
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<td>• Adaptive equipment</td>
<td>• Home modifications</td>
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<td>• Home modifications</td>
<td>• Financial assistance</td>
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<td>• Financial assistance</td>
<td>• Cash Subsidies</td>
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<td>• Short/Long term planning</td>
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<td>• Caregiver Supports and training</td>
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SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFE COURSE
COMPREHENSIVE, INTEGRATED, COORDINATED VISION

Pediatrician, Families and Friends, Faithbased

IDEA Part C, Parents as Teachers, Health, Headstart

School, Special Education, Health, Recreation

Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers

Retirement, Aging System, Health

Community

Family

Person with Disability
FORMAL AND INFORMAL SERVICES AND SUPPORTS

- **FORMAL**
  - GOVERNMENT
  - DISABILITY SPECIFIC NON-GOVERNMENTAL ORGANIZATIONS

- **PEER TO PEER EXCHANGE**
  - PEOPLE HELPING PEOPLE
  - FORMAL: ORGANIZED PROGRAMS
    - FAMILY ORGANIZATIONS
    - CO-OP
  - INFORMAL: NOT ORGANIZED THROUGH A PROGRAM
    - NEIGHBORS
    - EXTENDED FAMILY
    - FRIENDS

- **COMMUNITY ASSETS (INFORMAL OR NATURAL)**
  - COMMUNITY RESOURCES
  - BUSINESSES
  - RELIGIOUS BASED
Who funds formal services?

- Individual
  - Out of pocket
  - Private Health Insurance
- Local Government
  - School Districts
  - Tax Levees
    - Mental Health
    - Child Specific
    - Developmental Disabilities
- State Government
  - General Revenue
- Federal Government
  - Medicaid and Medicare
  - Title X: Maternal and Child Health Program
  - IDEA: Special Education
  - Social Security
FORMAL SERVICE MAZE: LIFE STAGES

Birth — Early Child — School — Transition — Adulthood — Aging

Charted

Uncharted with Supports

Person with Disability

Disability Services

Family

Community
FORMAL SERVICE MAZE: CATEGORIES

Pediatrician, Child Care, Parents Day Out, Head Start,
IDEA Part C, Parents as Teachers, Pediatrician
School, Special Education, Doctor, Afterschool Care,
Summer Care, Recreation
Vocational Rehab, Health, Employment, College, Military
Disability Services, Health, Housing, College, Careers
Retirement, Aging System, Health
FORMAL SERVICE MAZE: OTHER THINGS TO KEEP IN MIND

- Organized by “service areas” (districts, county, region)
- Eligibility
  - System specific or program specific
  - Specifically:
    - Diagnosis or functional limitation specific
    - Formal assessment
    - Financial
For Families with Members with Disabilities

FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE
WHO CAN HELP ME CREATE A VISION FOR MY FAMILY

- **INFORMAL:**
  - YOUR OWN BELIEFS AND EXPECTATIONS
  - FAMILY AND FRIENDS WHO KNOW AND BELIEVE IN YOUR CHILD

- **INFORMAL/FORMAL:**
  - OTHER FAMILIES WITH CHILDREN WITH DISABILITIES
  - SELF-ADVOCATES AND/OR ADULTS WITH DISABILITIES

- **FORMAL**
  - PROFESSIONALS
EXPLORING A VISION

- ON THE SIDELINES OF ACTIVITIES FOCUSED ON THE CHILD
  - WAITING ROOMS
  - RECREATIONAL AND SOCIAL EVENTS
- TRAINING AND EDUCATION OPPORTUNITIES
  - TOPIC OR SKILL SPECIFIC
  - VOLUNTEERING ON COMMITTEES OR QUALITY ASSURANCE ACTIVITIES
EXPLORING A VISION

- **FAMILY AND ADVOCACY NETWORKS**
  - MISSOURI FAMILY-TO-FAMILY AND SHARING OUR STRENGTHS
  - PEOPLE FIRST OF MISSOURI
  - ARC OF MISSOURI, TASH, FAMILY VOICES, AAIDD
  - DIAGNOSIS OR DISABILITY SPECIFIC

- **FAMILY ADVOCATES IN FORMAL ROLES**
  - DMH DDD FAMILY SUPPORT COORDINATORS
  - BSHCN FAMILY PARTNERSHIP PROGRAM
  - SYSTEMS OF CARE: PARENT PARTNERS
  - MENTAL HEALTH: PEER MENTORS
EXPLORING A VISION: FORMAL SERVICES

- What is the service called? Targeted Case Management
  - Assist with eligibility for certain services
  - Develop plans for services
  - Provide information
  - Connect to other formal and natural supports

- Who provides this support?
  - Service or Support Coordinators
  - Social Workers
  - Caseworker

- Example of types of systems that provide this service?
  - Early Childhood: First Steps
  - Health: MoHealth Net
  - Hospitals: Social Work Department
  - Social Services: Family Support Division
  - Developmental Disability: Regional Office or County SB40 Board
  - Special Health Care Needs: Bureau of Special Health Care Needs
  - Aging: Area Agency on Aging
DETERMINING SERVICE NEED BASED ON VISION FOR THE FUTURE
- New realities now that living environment disconnected from supports
- New roles and responsibilities for self-advocates and families
- New Possibilities
## Vision for the Future

### Not Yet Discovered
- ?????

### Uncharted
- Own home
- Shared Living Space
- Co-op
- Environmental Adaptations

### Slightly Charted
- Independent Supported Living

### Charted
- Training Centers
- Intermediate Care
- Group Homes
ERIC’S HOUSE

- WILL ERIC RENT OR OWN?
- DOES HE WANT TO LIVE IN AN APARTMENT, TOWNHOME OR HOUSE?
- SHOULD HE HAVE ROOMMATES?
- HOW MUCH COULD HE AFFORD FOR HOUSING COSTS?
- COULD HE RECEIVE FINANCIAL ASSISTANCE FROM HUD OR LOANS?
- COULD OUR FAMILY AFFORD TO SUPPORT ANY HOUSING COSTS?
## Vision for the Future

<table>
<thead>
<tr>
<th>Not Yet Discovered</th>
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<th>Slightly Charted</th>
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| • ??????            | • Remote Monitoring  
• Assistive Technology  
• Time banks  
• Human-service coops | • Self-directed Services  
• Respite  
• Micro-boards | • Staff hired by Provider |
• What was the intensity of supports Eric needed?
• What type of staff made sense for Eric’s needs?
• What level of daily support could our family provide?
• What level of control did we want over who his staff were?
WHO CAN HELP MAKE COMMUNITY LIVING A REALITY

- **INFORMAL:**
  - SUPPORTS:
    - FAMILY AND FRIENDS
    - ROOMMATES
  - HOUSING:
    - SHARED SPACE
    - ASSISTANCE WITH HOUSING

- **FORMAL**
  - SUPPORTS:
    - DDD SELF-DIRECTED SUPPORTS COORDINATOR
    - SUPPORTS COORDINATORS:
    - DIRECT SUPPORT PROFESSIONALS/PARA PROFESSIONALS
    - SHARED LIVING
  - HOUSING:
    - EARNED INCOME AND/OR SOCIAL SECURITY
    - LOANS AND BANKS
    - HOUSING AND URBAN DEVELOPMENT
## Vision for the Future

### Not Yet Discovered
- ????

### Uncharted
- Healthy Life Styles
- Preventative
- Universal Access
- Comprehensive Community based

### Slightly Charted
- Medical Home
- Patient Professional Partnerships
- Provider based

### Charted
- Medical Professionals Know Best
- Hospital Based

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**WHAT ABOUT HEALTH AND MEDICAL NEEDS?**
WHO CAN HELP MAKE HEALTHY LIFESTYLES A REALITY

- INFORMAL:
  - Patient Professional Partnerships
  - Education on healthy choices and lifestyles
  - Connections with Others
    - Spiritual
    - Recreational
    - Social

- FORMAL
  - Funding
    - Out of Pocket
    - Private Insurance
    - Public Insurance (Medicaid/EPSDT, Medicare)
  - Services
    - Behavioral Health
      - Counselors and Therapists
      - Psychiatrist/Psychologist
    - Health Medical Professionals
      - Doctors (Routine Care and Specialists)
      - OT/PT/Speech
### Vision for the Future

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<tr>
<td>• Micro-enterprise</td>
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<td>• College/Tech Schools</td>
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<td>• Career</td>
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<td>• Military</td>
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<tr>
<td>• Supported Employment</td>
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<td>• Volunteerism</td>
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<td>• AmeriCorps/VISTA</td>
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<tr>
<td>• Sheltered Workshops</td>
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<td>• Day Habilitation</td>
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• New generation growing up alongside peers
• Post-secondary education and Careers
• Economic Self-Sufficiency
• Increased access to social and recreation
• Valued role in community
WHO CAN HELP MAKE A MEANING DAY A REALITY

- INFORMAL:
  - FAMILY AND FRIENDS
  - PERSONAL CONNECTIONS

- FORMAL
  - SCHOOL DISTRICT
  - (GENERIC) COMMUNITY EMPLOYMENT RESOURCES
  - VOCATIONAL REHABILITATION
  - DDD EMPLOYMENT AND YOUTH SPECIALIST
### Vision for the Future

**Not Yet Discovered/Uncharted**
- Self-determination
- Emotional Well-being
- Personal Development
- Interpersonal Relationships
- Physical and Material Well-being
- Social Inclusion
- Rights

**Slightly Charted**
- Meaningful Roles
- Normalization

**Charted**
- Health and Safety
- Guardianship
VISION FOR A QUALITY OF LIFE

- Building own family and relationships
- Community connections provide quality assurance
- Fostering self-advocacy and self-determination skills leads to safety and protection
- Focusing on meaning of life beyond interventions and concrete day-to-day supports
MEETING NEEDS NOW AND VISIONING THE FUTURE

Uncharted with Supports

Charted

Community
Family
Person with Disability
Disability Services
Person with Disability
OUR UNCHARTED LIFE
NAVIGATING ERIC’S SUPPORTS

- **Division of Developmental Disabilities (DDD) Regional Office**
  - Administer funds for the Medicaid Home and Community Based Service Waiver (HCBS)
    - Residential Supports
    - Day Habilitation Services

- **SB40 Support Coordination**
  - Yearly Planning
  - Monitoring of Plan, Service and Funds

- **Provider:**
  - Companion Model for Residential Support Needs
  - Individualized Day Habilitation Program for Daily Supports

- **Specific Staff**
  - Nurse
  - House Manager (QDDP)
  - Companion Staff
  - Weekend Staff
  - Daily Staff
Community Supports
- Medical
- Educational
- Recreational
- Spiritual
- Social

Parents and Family
- Create a vision for his life
- Ensure access and quality of services
- Advocate for services (DDD, Doctor, Psychiatrist, Hospital, Provider)
- Maintain standards of quality of life (housing, clothes, extras)
- Continue to connect and build relationships
Life isn’t about how to survive the storm, but how to dance in the rain.
-unknown
REFERENCES


Family Support Agenda (2012). *Building a national agenda for supporting families with a member with intellectual and developmental disabilities.*


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