



# 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 SABLE)
  - Director of Mo **Family-to-Family**
  - Technical assistance to continue moving policy and practices to support the **"national agenda for supporting families with disabilities"**

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## MY FAMILY

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## 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

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## CHARTING A NEW REALITY

<b>Charted</b> <i>Traditional or familiar</i>	<b>Slightly Charted</b> <i>Tried but not norm</i>	<b>Uncharted</b> <i>New or unfamiliar</i>	<b>Unknown</b> <i>Not yet discovered</i>
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- 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

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## 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"**




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**WHERE WE ARE GOING**

Where we have been...

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**REAL LIVES, REAL PEOPLE...  
UNCHARTED LIVES**



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**UNCHARTED LIFE COURSE**



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### WHAT WE KNOW: CHARTED DISABILITY SERVICES



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### UNKNOWN VISION FOR THE FUTURE



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### WHAT WE WANT: SERVICES TO SUPPORT REAL LIVES



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## VISION FOR A FUTURE




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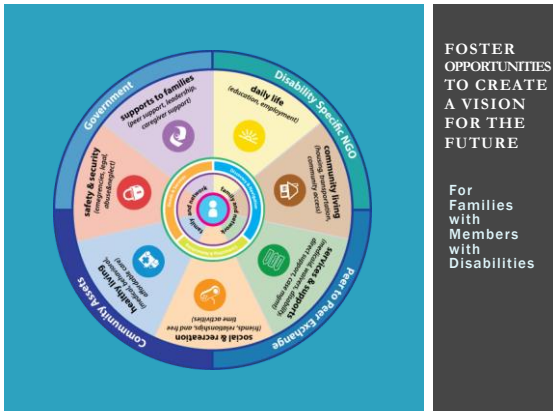
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FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE

For Families with Members with Disabilities

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## 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



\*National Definition for "Supporting Families" (2011 Wingspread)

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## 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.

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## FAMILY ROLES ACROSS LIFECOURSE

Caring About	Affection & Self-Esteem
	Repository of knowledge
	Lifetime commitment
Caring For	Provider of day-to-day care
	Material/Financial
	Facilitator of inclusion, recreation, spirituality & meaningful activities
	Advocate for support

Bigby & Fyffe (2012), Daily (1988), Turnbull et al (2011)

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## CHARTER FOR SUPPORTS

<b>DISCOVERY AND NAVIGATION</b> Information and Training Supports	<b>PEER SUPPORT NETWORKS</b> Emotional Supports	<b>DAY-TO-DAY NEEDS</b> Services for Daily Needs
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## SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFECOURSE

<b>Information and Training Supports:</b> <i>Knowledge and Skills</i>	<b>Emotional Supports:</b> <i>Mental Health and Self-efficacy</i>	<b>Day-to-Day Supports:</b> <i>Services for Daily Needs</i>
<ul style="list-style-type: none"> <li>Information on disability</li> <li>Knowledge about best practices and values</li> <li>Skills to navigate and access services</li> <li>Ability to advocate for services and policy change</li> </ul>		

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## SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFECOURSE

<b>Information and Training Supports:</b> <i>Knowledge and Skills</i>	<b>Emotional Supports:</b> <i>Mental Health and Self-efficacy</i>	<b>Day-to-Day Supports:</b> <i>Services for Daily Needs</i>
	<ul style="list-style-type: none"> <li>Parent-to-Parent Support</li> <li>Self-Advocacy Organizations</li> <li>Family Organizations</li> <li>Sib-shops</li> <li>Support Groups</li> <li>Professional Counseling</li> <li>Non-disability community support</li> </ul>	

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## SUPPORTING INDIVIDUALS AND FAMILIES ACROSS THE LIFECOURSE

<b>Information and Training Supports:</b> <i>Knowledge and Skills</i>	<b>Emotional Supports:</b> <i>Mental Health and Self-efficacy</i>	<b>Day-to-Day Supports:</b> <i>Services for Daily Needs</i>
		<ul style="list-style-type: none"> <li>Self/Family-Directed services</li> <li>Transportation</li> <li>Respite/Childcare</li> <li>Adaptive equipment</li> <li>Home modifications</li> <li>Financial assistance</li> <li>Cash Subsidies</li> <li>Short/Long term planning</li> <li>Caregiver Supports and training</li> </ul>

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## COMPREHENSIVE, INTEGRATED, COORDINATED VISION

Pediatrician, Families and Friends, Faithbased

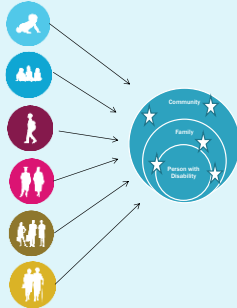
IDEA Part C, Parents as Teachers, Health, Headstart

School, Special Education, Health, Recreation

Vocational Rehab, Health Employment, College, Military

Disability Services, Health, Housing, College, Careers

Retirement, Aging System, Health




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## 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




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## FORMAL SERVICES AND SUPPORTS

- 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

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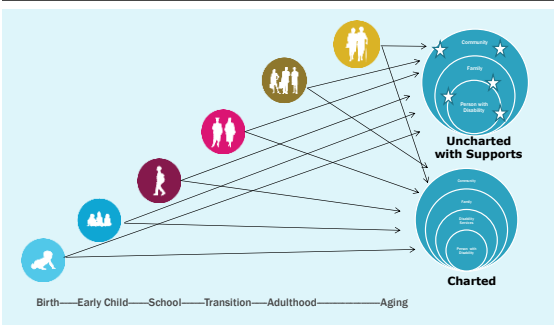
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## FORMAL SERVICE MAZE: LIFE STAGES




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## 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 

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## 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

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**FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE**

For Families with Members with Disabilities

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**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

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**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

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## 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

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## 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

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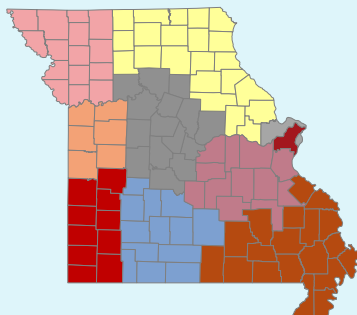
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## MO FIRST STEPS: SYSTEM POINT OF ENTRY (SPOE)




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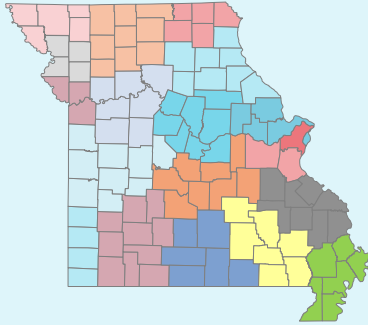
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**MO HEAD START**



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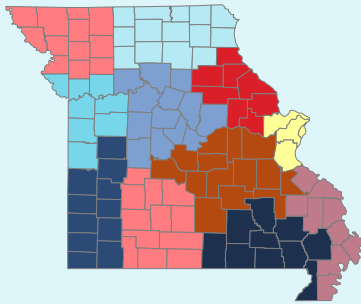
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**DMH Division of Developmental Disabilities:  
Regional Offices**



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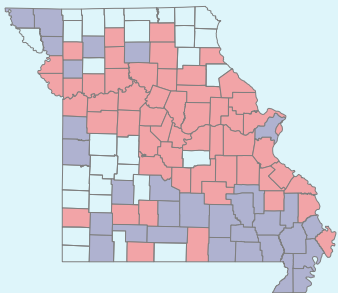
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**DEVELOPMENTAL DISABILITY  
LOCAL COUNTY SB40 BOARDS**



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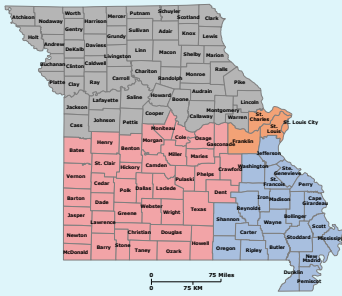
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### DHSS HEALTHY CHILDREN AND YOUTH




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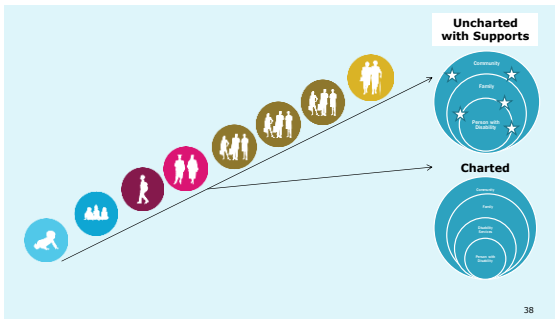
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### DETERMINING SERVICE NEED BASED ON VISION FOR THE FUTURE




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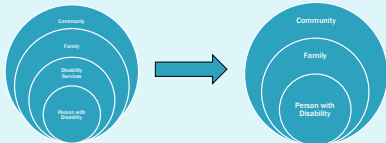
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### **VISION FOR COMMUNITY LIVING**



- New realities now that living environment disconnected from supports
- New roles and responsibilities for self-advocates and families
- New Possibilities

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## WHERE WILL I LIVE?

Vision for the Future
Not Yet Discovered
• ?????
Uncharted
<ul style="list-style-type: none"> <li>• Own home</li> <li>• Shared Living Space</li> <li>• Co-op</li> <li>• Environmental Adaptations</li> </ul>
Slightly Charted
• Independent Supported Living
Charted
<ul style="list-style-type: none"> <li>• Training Centers</li> <li>• Intermediate Care</li> <li>• Group Homes</li> </ul>

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## 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?

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## WHO WILL SUPPORT ME?

Vision for the Future
Not Yet Discovered
• ?????
Uncharted
<ul style="list-style-type: none"> <li>• Remote Monitoring</li> <li>• Assistive Technology</li> <li>• Time banks</li> <li>• Human-service coops</li> </ul>
Slightly Charted
<ul style="list-style-type: none"> <li>• Self-directed Services</li> <li>• Respite</li> <li>• Micro-boards</li> </ul>
Charted
• Staff hired by Provider

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## ERIC'S SUPPORTS

- 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?




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## 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

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## WHAT ABOUT HEALTH AND MEDICAL NEEDS?

<b>Vision for the Future</b>
<b>Not Yet Discovered</b>
<ul style="list-style-type: none"> <li>• ?????</li> </ul>
<b>Uncharted</b>
<ul style="list-style-type: none"> <li>• Healthy Life Styles</li> <li>• Preventative</li> <li>• Universal Access</li> <li>• Comprehensive Community based</li> </ul>
<b>Slightly Charted</b>
<ul style="list-style-type: none"> <li>• Medical Home</li> <li>• Patient Professional Partnerships</li> <li>• Provider based</li> </ul>
<b>Charted</b>
<ul style="list-style-type: none"> <li>• Medical Professionals Know Best</li> <li>• Hospital Based</li> </ul>

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## 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

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## WHAT WILL I DO DURING THE DAY?

<b>Isolation for the Future</b>
<b>Not Yet Discovered</b>
• ?????
<b>Uncharted</b>
• Micro-enterprise
• College/Tech Schools
• Career
• Military
<b>Slightly Charted</b>
• Supported Employment
• Volunteerism
• AmeriCorps/VISTA
<b>Charted</b>
• Sheltered Workshops
• Day Habilitation




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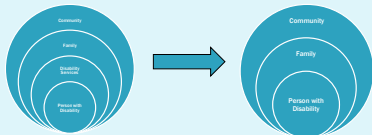
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## VISION FOR A MEANINGFUL DAY



- New generation growing up alongside peers
- Post-secondary education and Careers
- Economic Self-Sufficiency
- Increased access to social and recreation
- Valued role in community

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## 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

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## 👤 **WHAT ABOUT OUR QUALITY OF LIFE?**

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**Vision for the Future**

<b>Not Yet Discovered/Uncharted</b>
<ul style="list-style-type: none"> <li>Self-determination</li> <li>Emotional Well-being</li> <li>Personal Development</li> <li>Interpersonal Relationships</li> <li>Physical and Material Well-being</li> <li>Social Inclusion</li> <li>Rights</li> </ul>
<b>Slightly Charted</b>
<ul style="list-style-type: none"> <li>Meaningful Roles</li> <li>Normalization</li> </ul>
<b>Charted</b>
<ul style="list-style-type: none"> <li>Health and Safety</li> <li>Guardianship</li> </ul>

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## ★ **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

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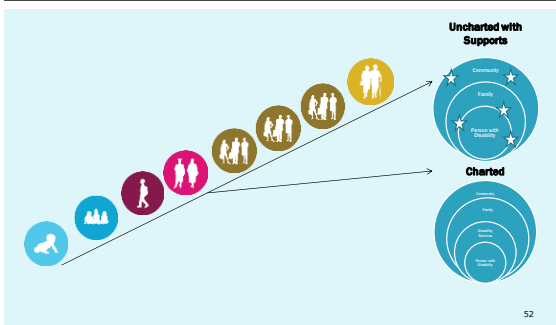
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## MEETING NEEDS NOW AND VISIONING THE FUTURE




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## OUR UNCHARTED LIFE




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## 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

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## NAVIGATING ERIC'S SUPPORTS

- Community Supports
  - Medical
  - Educational
  - Recreational
  - Spiritual
  - Social
- Parents and Family
  - Create a vision for his life
  - Ensure access and quality to services
  - Advocate for services (DDD, Doctor, Psychiatrist, Hospital, Provider)
  - Maintain standards of quality of life (housing, clothes, extras)
  - Continue to connect and build relationships

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**Life Isn't  
about how  
to survive  
the storm,  
but how  
to dance  
in the  
rain.**  
-unknown

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