Michelle Reynolds, PhD
Director of Individual Advocacy and Family Support
UMKC Institute for Human Development
University Center on Excellence in Developmental Disabilities
Kansas City, MO

Charting a Life Course:
A Framework and Strategies for Supporting Individuals with Developmental Disabilities and Their Families

November 2, 2012
Doubletree Suites, Mt. Laurel
Charting a New Life Course:  
A Framework and Strategies for  
Supporting Individuals with Developmental Disabilities and Their Families

Michelle “Sheli” Reynolds, SIBLING, PhD  
Missouri Family-to-Family Resource Center  
University of Missouri-Kansas City  
Institute for Human Development  
University Center on Developmental Disabilities  
November 2, 2012

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 Disability & Health Information Center

My Family

Goals of Presentation
- Challenge everyone to think beyond their current beliefs and understanding
- Show the impact of history on supports and services now
- Provide an overview of the role of the family throughout the lifespan
- Describe a new agenda for supports to individuals and their families across the life course

Charting a New Reality

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

Real Lives, Real People….Uncharted Lives

Community
Family
Person

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

Healthy & Safe

Future of Disability Services: Uncharted Lives

Community
Family
Person with Disability
Vision for a Future

Services
Healthy & Happy
Friends & Family
Supports
Financial

Making Connections, Finding Solutions Together

WHO ARE WE TALKING ABOUT?

Who in the Nation are we Talking About?

<table>
<thead>
<tr>
<th></th>
<th>National</th>
<th>Living Natural Home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Est. Number of Persons with DD</td>
<td>4.7 Million*</td>
<td></td>
</tr>
<tr>
<td>Receiving State DD Services (25%)</td>
<td>1.2 Million*</td>
<td></td>
</tr>
<tr>
<td>Of the 25% receiving Services</td>
<td>528,000 (44%)*</td>
<td>672,000 (56%)</td>
</tr>
<tr>
<td>Not receiving State DD Services (75%)</td>
<td></td>
<td>3.5 Million</td>
</tr>
<tr>
<td>Total Persons with DD Living in Home in Community</td>
<td>4.17 Million</td>
<td></td>
</tr>
</tbody>
</table>


Another way to look at the numbers....

<table>
<thead>
<tr>
<th>Total Persons with DD Living in Homes in Community</th>
<th>4.17 Million</th>
<th>87%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total Persons with DD Living in Residential</td>
<td>528,000</td>
<td>13%</td>
</tr>
<tr>
<td>Total Persons with DD</td>
<td>4.7 Million</td>
<td>100%</td>
</tr>
</tbody>
</table>


Developmental Disability Act, 2000

- Disability is a natural part of the human experience
- not diminish the right of individuals with developmental disabilities to
  - enjoy the opportunity to live independently,
  - enjoy self-determination,
  - make choices,
  - contribute to society and
  - experience full integration and inclusion in the economic, political, social, cultural, and educational, mainstream of American Society.

For Individuals with Disabilities:
FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE
Vision for the Future

Where will I Live?
- Shared Living Space
- Co-op
- Environmental Adaptations
- Independent Supported Living
- Home of Your Own
- Training Centers
- Intermediate Care
- Group Homes

Who will Support Me?
- Remote Monitoring
- Assistive Technology
- Time banks
- Human-service coops
- Self-directed Services
- Respite
- Micro-boards
- Staff hired by Provider

What will I do for a living?
- Micro-enterprise
- College/Tech Schools
- Career
- Military
- Supported Employment
- Volunteerism
- AmeriCorps/VISTA
- Sheltered Workshops
- Day Habilitation

What about my Quality of Life?
- Self-determination
- Emotional Well-being
- Personal Development
- Interpersonal Relationships
- Physical Well-being
- Material Well-being
- Social Inclusion
- Rights
- Meaningful Roles
- Normalization
- Health and Safety

Family Support and My Family

For Families with Members with Disabilities:
FOSTER OPPORTUNITIES TO CREATE A VISION FOR THE FUTURE
History of the Role of Family

<table>
<thead>
<tr>
<th>Era</th>
<th>Understanding of Family</th>
<th>Disability Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>1800s-</td>
<td>Moral blame assigned to parents</td>
<td>Removal from Society</td>
</tr>
<tr>
<td>1900s</td>
<td>Child damaged families</td>
<td>Removal from Family</td>
</tr>
<tr>
<td>1950s</td>
<td>Burden of Caregiving</td>
<td>Specialized Therapeutic Congregate Services</td>
</tr>
<tr>
<td>1980s</td>
<td>Families seen as system</td>
<td>Community Group Residential Supports</td>
</tr>
<tr>
<td>1990s</td>
<td>Families support children to remain in their home for as</td>
<td>Family Support programs for children living</td>
</tr>
<tr>
<td></td>
<td>long as possible</td>
<td>at home</td>
</tr>
</tbody>
</table>

History of the Role of Family

<table>
<thead>
<tr>
<th>Era</th>
<th>Understanding of Family</th>
<th>Disability Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>2010s</td>
<td>Families adapt, accommodate and are resilient</td>
<td>-Family is a main constant in the lives of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>persons with disability</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Families play significant role</td>
</tr>
<tr>
<td></td>
<td></td>
<td>across the lifespan regardless of</td>
</tr>
<tr>
<td></td>
<td></td>
<td>service provision</td>
</tr>
<tr>
<td></td>
<td></td>
<td>-Families may need supports for</td>
</tr>
<tr>
<td></td>
<td></td>
<td>the different roles they play in the</td>
</tr>
<tr>
<td></td>
<td></td>
<td>lives of their family member</td>
</tr>
</tbody>
</table>

Family Role Across the Life Course

- Caregiver and Family
- Behavior Therapist
- Spiritual Guider
- Psychiatrist or Counselor
- Social Planner
- Life Coordinator
- Protector and Advocate

Cared about and Loved
- Self-determined
- Independent/interdependent
- Integrated and Included
- Meaningful life

Family Roles

| Caring About           | Affection                     | Repository of knowledge                      |
|                       | Emotional Support             | Lifetime commitment                           |
|                       | Unconditional love           | Provider of day-to-day care                   |
|                       | Emotional closeness          | Material/Financial                             |
|                       | Self-Esteem                  | Facilitator of inclusion, recreation,         |
|                       | Individuality                | spirituality & meaningful activities          |
|                       | Unconditional membership role (child, sibling, aunt) | Advocate for support                        |
|                       | Deep connections to other community members |                                                 |

Caring About……

- Emotional Support
  - Affection
    - Unconditional love
    - Emotional closeness
  - Self-Esteem
    - Individuality
    - Unconditional membership role (child, sibling, aunt)
    - Deep connections to other community members

Love, Connections, Belonging, Meaning
Protection and safety

Caring about…… (continued)

- Repository of knowledge
  - Communication styles and habits
  - Culture, values, beliefs, traditions
  - Interpreter of life story
- Lifetime commitment
  - Long-term view
  - Futures planning
Caring For……

- Provide day-to-day care
- Material or financial support
- Facilitate inclusion, recreation, spirituality and meaningful activities
- Advocate for Services
  - Negotiator
  - Gatekeeper to services/consent
  - Monitor Quality
  - Complainant

What we Know about Families

- Unconditional love for their child
- Resilient and accommodating
- Feeling Alone and Afraid
- Lack of Information
- Unknown Vision for Future
- Hard to Navigate

Objective of Supports for Families

To support families, with all their complexity and diversity, in ways that maximizes their capacity, strengths and unique abilities

so they can best support, nurture, love and facilitate

the achievement of self-determination, interdependence, productivity, integration and inclusion in all facets of community life for their family members.


New Supports for Families

<table>
<thead>
<tr>
<th>Charted</th>
<th>New Charter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Defined by eligibility, services or programs available, or funding</td>
<td>Not a program or based on eligibility, it is needs defined by the families</td>
</tr>
<tr>
<td>Caregiver or parent</td>
<td>Family is defined functionally, inclusive of siblings, parents with disabilities, grandparents</td>
</tr>
<tr>
<td>Tension between self-advocacy and family support</td>
<td>Enhances opportunities for self-advocacy and self-determination</td>
</tr>
<tr>
<td>Crisis, immediate response</td>
<td>Preventative, long-term planning</td>
</tr>
<tr>
<td>Supporting caregiver in order to decrease demand on long-term services</td>
<td>Creates a quality of life for person with DD and their family</td>
</tr>
</tbody>
</table>

Supporting the Individual with DD in the Family System

Individual:
- Supports and services to achieve self-determination, interdependence, integration & Inclusion and productivity

Supporting Family System:
- Information and Training
- Peer Support Networks
- Day-to-Day Supports

Birth—Early Child—School—Transition---------Adulthood-----------------------------Aging
# New Charter for Family Supports

**DISCOVERY AND NAVIGATION**
- Information and Training Supports

**PEER SUPPORT NETWORKS**
- Emotional Supports

**DAY-TO-DAY NEEDS**
- Supports for Role of Daily Care/Support

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## Supporting Individuals and Families Across the Lifecourse

### Information and Training Supports: Knowledge and Skills
- **Emotional Supports:** Mental Health and Self-efficacy
- **Instrumental Supports:** Day-to-Day Needs

<table>
<thead>
<tr>
<th>Information and Training Supports: Knowledge and Skills</th>
<th>Emotional Supports: Mental Health and Self-efficacy</th>
<th>Instrumental Supports: Day-to-Day Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Information on disability</td>
<td>• Knowledge about best practices and values</td>
<td>• Parent-to-Parent Support</td>
</tr>
<tr>
<td>• Skills to navigate and access services</td>
<td>• Ability to advocate for services and policy change</td>
<td>• Self-Advocacy Organizations</td>
</tr>
<tr>
<td>• Ability to advocate for services and policy change</td>
<td></td>
<td>• Family Organizations</td>
</tr>
</tbody>
</table>

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## Navigation: Skills

<table>
<thead>
<tr>
<th>Chartered</th>
<th>Unchartered</th>
</tr>
</thead>
<tbody>
<tr>
<td>Knowledge on how to navigate and access services</td>
<td>Available services and eligibility criteria</td>
</tr>
<tr>
<td>Understanding and ability to navigate and access different supports within and outside of disability services</td>
<td></td>
</tr>
<tr>
<td>Skills to plan for current needs while focusing on a vision for the future</td>
<td>Person-centered/family-centered planning</td>
</tr>
<tr>
<td>Building social capital and relationships, developing economic self-sufficiency, long term planning</td>
<td>Individual Education Plans</td>
</tr>
<tr>
<td>Ability to advocate for services and policy change</td>
<td>Understand rights and responsibilities</td>
</tr>
<tr>
<td>Enhance skills to make a change for self, family and for services and systems</td>
<td></td>
</tr>
</tbody>
</table>

---

## 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>Instrumental Supports: Day-to-Day Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Respite/Childcare</td>
<td>• Parent-to-Parent Support</td>
<td>• Cash Subsidies</td>
</tr>
<tr>
<td>• Adaptive equipment</td>
<td>• Self-Advocacy Organizations</td>
<td>• Short/Long term planning with family</td>
</tr>
<tr>
<td>• Home modifications</td>
<td>• Support Groups</td>
<td></td>
</tr>
<tr>
<td>• Financial assistance</td>
<td>• Professional Counseling</td>
<td></td>
</tr>
<tr>
<td>• Cash Subsidies</td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Short/Long term planning with family</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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Life Course Perspective and Formal Service Systems

**REFOCUSING TO RESPOND TO INDIVIDUALS AND FAMILY VISIONS**
What is the Life Course Perspective?

- Looks at areas across the life span
  - Not disconnected stages
  - Each life stage influences the next
- Complex interplay of
  - Biological
  - Behavioral
  - Psychological
  - Social
  - Environmental factors

Policy Brief: A New Agenda for MCH Policy and Programs (2009)

Life Course Perspective:

- Humans are capable of making choices and creating their own life journeys, within opportunities and constraints
- Looks at the impact of historical environmental events and early life experiences on adulthood.
- Humans are interdependent, with family as the primary arena for experiencing and interpreting the social world

Hutchison, E.D. (2007) A Life Course Perspective

Life Course Perspective: Basic Concepts

- **Trajectory:** Long-term pattern of stability and change, which usually involves multiple transitions.
- **Transition:** Change in roles and statuses that represents a distinct departure from prior roles and statuses.

An Example: Health

- **Causes of Heart Disease**
  - Adult Lifestyle Model
    - Change current behaviors
      - Smoking
      - Diet
      - Exercise
      - Alcohol consumption
  - Life Course Perspective
    - Biological and Social Factors
    - Starting at pregnancy and building throughout lifespan


Applying Life Course to Disability Systems

- Supporting the Individual
  - “system of supports and services to achieve self-determination, interdependence, integration, inclusion and productivity”
- Supporting the Family
  - “system of supports and services for discovery and navigation, connecting with others and to support the caregiving/support role”

Life Course: Basic Concepts
Trajectory of Life with Disability

What are you doing to support a Uncharted Life??

Birth---Early Child---School---Transition---Adulthood---Aging

Vision for Community Living

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

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

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

Life Course: Basic Concepts

- Turning Point: Life event that produces a lasting shift in the life course trajectory
- Life event: significant occurrence involving a relatively abrupt change that may produce serious and long-lasting effects

Life Course Perspective

TURNING POINTS
Decrease Negative Turning Points
- Lack of relief from financial, physical and emotional strains
- Constant crisis with loved one or family
- Negative social stigma
- Barriers within “systems” that destroy a vision for the future (policies and culture)

Increase Positive Turning Points
- Learning from others who “walk the walk” (peer-to-peer exchange)
- Seeing it to believe it!! (Successful Lives)
- Training on How and Educating on Why
- Starting before change, transition or crisis
- Consistent and on-going message

Fostering Expectations for the Future!!

Moving Beyond the “What” to “Why and How”

<table>
<thead>
<tr>
<th>Information on disability</th>
<th>What</th>
<th>Why</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific diagnosis and interventions, therapies, and services</td>
<td>Personal stories of hope, possibilities, and opportunities for now and the future</td>
<td></td>
</tr>
</tbody>
</table>

Knowledge about best practices, values, and philosophy
- Housing
- Education
- Employment
- Sexuality
- Health care
- Early childhood
- Recreation
- Inclusion and integration
- Productivity and meaningful life
- Self-Determination
- Social Capital
- Natural Supports
- Family/person-centered thinking

Strategies for Turning Points

<table>
<thead>
<tr>
<th>Charted</th>
<th>Uncharted</th>
</tr>
</thead>
</table>
| Now it is provided | • In-person Workshops
• Directories
• Booklets
• Websites
• Support Groups |
| • Webinars
• Community Conversations
• Blogs, chat rooms
• Videos, pictures, personal testimonies
• Social Media
• Text messages |

Employment Across the Life Course

- Start young
- Start small
- Match to interests and abilities
- Make it a lifetime habit
Young Child

- Chores around the house
- Helping neighbors or grandparents
- Volunteering at church or in community

School Age

- School based clubs or organizations
- Classroom Aid or Office Helper
- Helping a neighbor, grandparents, family
- Community based (scouts, church, service)

Transition Age

- IEP goals focusing on employment
- Part Time Jobs
- Internships
- Extra curricular activities
- Volunteer
- Job exploration
- Paying for College

Ben’s Transition Story

- Wanted More for Ben
- Identified 2 places he could volunteer
- School provided staff support
- Local public transportation
- Community connections
- Now part of adult life

Adult Life

- Career
- Volunteerism
- Military
- College
- Business Owner
- Virtual Work
- AmeriCorps

Aging

- Retiring from work or day activities
- Staying connected in the community
- Making new friends as old ones are gone
- Adjusting to new life realities
Fostering Self-Determination

Learning to be more self-determined starts early and continues throughout the life course.

Self-Determination Across the Life Course

- Promote making choices
- Encourage exploring possibilities
- Promote reasonable risk taking
- Promote advocacy
- Help develop self-esteem
- Help set goals and plan
- Help understand the disabilities/special needs
- Encourage problem solving

National Gateway to Self-Determination (2011)

Housing

- Identify different options for where my child might live when they are an adult/high school
- Who does my child want to live with
- Discuss different living options & pros and cons of each with them
- Visit different housing environments (apartments, dorms, own home, family home modified)

Services, Supports, Financial

- Open a joint bank account for the youth
- Limited bank account/debit card
- Give plenty of opportunities to practice
- Help them learn about deciding how to spend money
- Involve child in meetings about services and supports
- Talk about how money earned from employment might affect benefits such as social security

Social & Recreation

- Explore their interests so they can become involved in groups, clubs and other social opportunities of their choosing
- Introduce to new people and places
- Support the development of friends and connections in the community
- Help your child build “social capital”

Health & Wellness

- Help your child understand their disability, special healthcare need, everyday health needs
- Teach how to interact with doctors and medical professionals, including how to explain their own needs
- Teach what to do/how to get help when they are not well
- Begin helping your child to manage their own medications
- Let your child pay for medical care using their insurance card
- Talk to them about their reproductive health and responsibilities
Safety & Security
- Teach the youth what to do in an emergency
- Practice drills – fire, tornado, etc.
- Give them opportunities to learn how to get around town – ride the bus, cross the street safely, etc.
- Give them tools to be able to communicate their needs, problems, etc. to others

Family Support
- Begin shifting responsibility to the youth in whatever areas you can
- Start letting go of some of the control and decision making power
- Connect your child to a self-advocacy or leadership group
- Begin viewing your child as an adult!

Building Capacity to Support “Visions”
DIRECT SERVICES, FAMILIES AND PROFESSIONALS

Supporting ALL Families

Partnering to Support Individual Visions

<table>
<thead>
<tr>
<th>Family</th>
<th>Formal Supports</th>
</tr>
</thead>
<tbody>
<tr>
<td>Affection &amp; Self-Esteem</td>
<td></td>
</tr>
<tr>
<td>Repository of knowledge</td>
<td></td>
</tr>
<tr>
<td>Lifetime commitment</td>
<td></td>
</tr>
<tr>
<td>Provider of day-to-day care</td>
<td></td>
</tr>
<tr>
<td>Material/Financial</td>
<td></td>
</tr>
<tr>
<td>Facilitator of inclusion, recreation, spirituality &amp; meaningful activities</td>
<td></td>
</tr>
<tr>
<td>Advocate for support</td>
<td></td>
</tr>
</tbody>
</table>

Building Capacity to Support “Visions”
- Understanding history of field
- Focus on self-determination and civil rights
- Caregiving vs. supporting
- Becoming part of the fabric of life
- Balancing outcomes of individual and family
- Utilizing the knowledge, love and experience of families
- Working in others home and environments
Examples of Supporting Relationship and Culture of Family

- Ensure Cultural and Family Traditions: environment, food, schedules, values and beliefs, and spirituality
- Support participation in Family Holidays and Events: holidays, funerals, vacations, birthdays, weddings, graduations
- Facilitate reciprocal connections with family members: communication, gifts, special activities
- Building “family” to fulfill lifelong commitment roles

Life Course Perspective
BUILDING COMMUNITY CAPACITY TO SUPPORT “VISIONS”

Building Capacity of COMMUNITY STARS

- Training and education to support change
- Opportunities to learn, explore, make mistakes
- Brainstorming and Problem Solving Groups
  - Community of Practice
  - Community Conversations
- Peer-to-peer exchange
  - Professionals
  - Direct care workers
  - Families Utilizing New Waivers/Services

Types of Activities to Build Capacity

Vision for All People with Disabilities

- Disablity Policy
- 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.
Vision for Services for People with Disabilities

- Health and safety while respecting the rights of individuals
- Community-based supports
- Full, integrated, competitive employment
- Individual choice, natural relationships and equity in the provision of supports and services

Policies & Systems: Integrated, Coordinated Vision

- Pediatrician, Families and Friends, Faith-based
- IDEA Part C, Parents as Teachers, Headstart
- School, Special Education, Recreation
- Vocational Rehab, Employment, College, Military
- Disability Services, Housing, College, Careers
- Retirement, Aging System

Moving Policy to Support Uncharted Lives

Policy to Support Changing Cohorts

"Lag between social change and the development of public policy to respond to new circumstances and the needs that arise with social change AND vice versa."

- Disability Civil Rights Movement
- Individuals with Disabilities Education Act
- Medicaid Waiver


Real Life and Policy

- Individualized and flexible enough to meet on-going needs of different and evolving "cohorts"
- Written from "now" and not building on "old"
- Encourages and integrates multitude of formal and informal supports
- Provides opportunities to build the capacity to implement the new policy or paradigm

MAKING CONNECTIONS:
FINDING SOLUTIONS TOGETHER
Making Connections: Finding Solutions Together

- Supports **WITHIN AND BEYOND** the disability service system across the lifespan
- Help persons with disability and their families **PLAN FOR POSSIBILITIES** and dreams before crisis, life-transitions and future
- Define **EXPECTATIONS**, roles and responsibility of service system, individuals, their families and their community
- Provide **PREVENTIVE SUPPORTS** to lessen the intensity, frequency and long-term nature of crisis services.

---

References


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


References (continued)


Contact Information

Sheli Reynolds
reynoldsmc@umkc.edu
816.235.1759
References


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


References (continued)


