



Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities



**Building a National Agenda for Supporting Families
with a Member with Intellectual and Developmental Disabilities**



Community of Practice for Supporting Families of Individuals with Intellectual & Developmental Disabilities

About the Community of Practice

The National Community of Practice for Supporting Families of Individuals with Intellectual and Developmental Disabilities will help five states develop systems of support for families throughout the lifespan of their family member with intellectual and developmental disabilities. The objective of the grant is to develop systems of supports for families throughout the lifespan of their family member.

Facilitating the Community of Practice

Grant partners include

- National Association of State Directors for Developmental Disability Services (NASDDDS)
- University of Missouri-Kansas City – Institute for Human Development (UMKC-IHD)
- Human Services Research Institute (HSRI)
- National Association of Councils on Developmental Disabilities (NACDD)

Goals of the CoP

The goals of the Community of Practice are:

- to create a model framework for supporting families that addresses the needs of families with a family member with I/DD across the lifespan and supports states to develop and sustain exemplary family support practices.
- to develop and facilitate a multi-level Community of Practice designed to build capacity within states and the nation to create policies, practices, and systems to better assist and support families that include a member with I/DD across the lifespan.
- to capture and share lessons learned and products to develop, implement and sustain exemplary practices to support families and systems

The Goal of Supporting Families

The overall goal of supporting families, with all of their complexity, strengths and unique abilities is so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members.



from Building a National Agenda for Supporting Families with Member with I/DD 2011

Goal: To create a model framework for supporting families that addresses the needs of families with a family member with ID/DD across the lifespan.

Wingspread Report

<http://www.ct.gov/dds/cwp/view.asp?a=2042&Q=537862>

GRANT STATES*

CONNECTICUT
DISTRICT OF COLUMBIA
*MISSOURI
OKLAHOMA
TENNESSEE
WASHINGTON

Learn about policies and practices for supporting families, find resources connect with the Community of Practice, and share your ideas about supporting families:



Visit our website at www.supportstofamilies.org



Like us on Facebook at facebook.com/supportstofamilies



Sign up for our mailing list at www.supportstofamilies.org



Follow us on Twitter at twitter.com/familieswithidd

The Community of Practice (CoP) Supporting Families throughout the Lifespan is operated under a five year grant awarded to NASDDDS by the Administration on Intellectual and Developmental Disabilities (AIDD) beginning October 2012.

CHARTING the life course



What is Charting the Life Course?



Framework for Supporting Individuals and Families throughout the Life Course

Charting the Life Course is a framework that was developed to help individuals with disabilities and families at any age or stage of life think about what they need to know, identify how to find or develop supports, and discover what it takes to live the lives they want to live. Individuals and families can focus on their current situation and stage of life but may also find it helpful to look ahead to start thinking about what they can do or learn now that will help build an inclusive, productive life in the future.

- Life is a journey - Our lives are not static, they change every day.
- It's all about vision - Anything is possible, with the right vision.
- Everything is connected - What you do today affects your life in the future.
- Our overall compass for people with disabilities and their families is "quality of life."

Supporting Families Community of Practice



<http://supportstofamilies.org/cop/>

GOAL

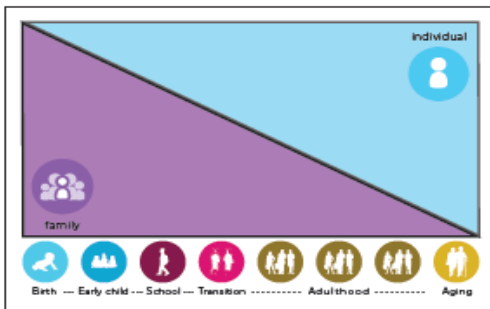


Individual
Will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life



Families
Will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support the individual to achieve their goal





Recognizing that individuals exist within a family system



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 and meaningful activities
	Advocate for support

- 10 Committees
- Family-to-Family Connections
- Employment
- Healthy Living
- Housing/Home Supports
- Information Navigation
- Person-Centered Planning
- Positive Behavior Support
- Respite/Social Opportunities
- Self-Directed/In-Home Supports
- Technology

Re-evaluating current services – How many could we serve?

Type of Service	Cost per Person	Cost to Serve the Waiting List 122,870	People Served with \$5 M
ICF/MR	\$128,275 CT \$383,316	\$15,761,114,925	 39 CT 13
Non-family HCBS	\$70,133 CT \$140,199	\$8,617,241,710	 71 CT 36
Host Family	\$44,122 CT \$51,687	\$5,421,270,140	 113 CT 97
Own Family	\$25,072 CT \$30,390	\$3,080,596,640	 200 165

Data Source: Lakin, K.C. MSIS and NCI data from 4 states (1,240 Individuals)

NASDDDS

National Association of State Directors of Developmental Disabilities Services

What We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change...
System Change Learning takes time	We are moving into a new generation of services. It is hard to let go of the familiar.	Partnerships: Stakeholders move from fear-based responses to hope-based action planning



What We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change...
Family Engagement Families benefit from collaborations with other families	Isolated families result in increased needs over-time	Funding for family networking, mentoring, training and care-giving supports are available to assist families to be resilient and to support new ideas



What We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change...
Community Engagement & Reciprocal Contribution	Stakeholders often ask for help from the community without showing how reciprocal contributions will occur.	Training: Stakeholders learn the art & science of “crossing thresholds” and develop community partnerships based upon equality & mutual reward



What We've Learned Through the Supporting Families Community of Practice

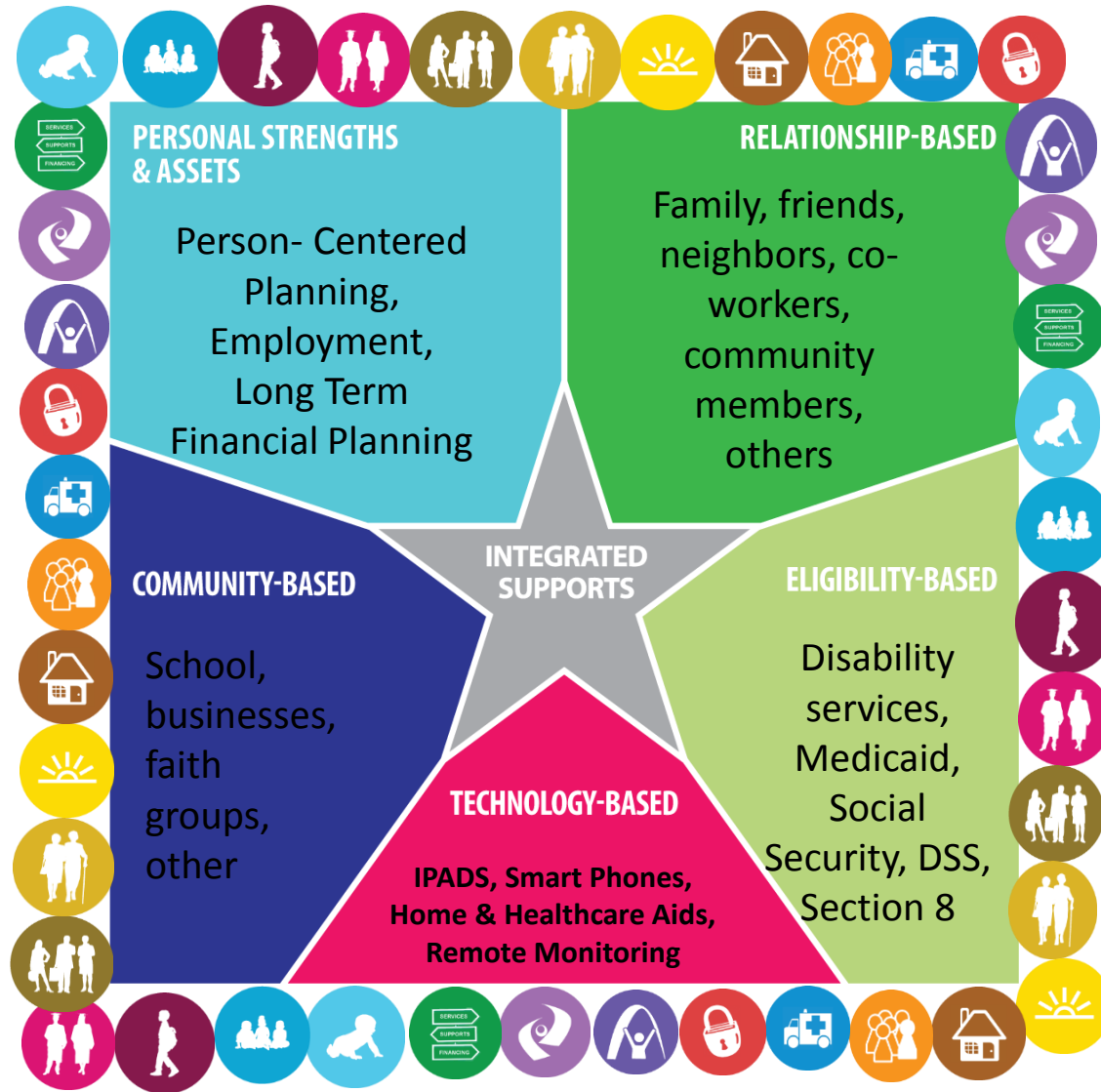
LEARNING	BARRIERS	What we hope will change...
<p>Life Course Principles Helping families build upon life stages is more effective than waiting for people to arrive at the door of adult services</p>	<p>IDD services are not as effective or efficient as they can be when provided in a silo, or when services are separated from previous developmental stages</p>	<p>Staffing: Partnering with practitioners from each life stage reduces duplication of services & helps lead to better outcomes for people with IDD. Appropriate support is available at each life stage.</p>



What We've Learned Through the Supporting Families Community of Practice

Lifespan Areas of Change	Accomplishments	Future Next Steps
Messaging	Posters, Displays, DDS Family Website, Bookmark	COP Website, Videos, Success Stories, DDS 101 updates
Positions	Youth Coordinator, Transition & Education Advisors, Case Managers, Family Resource Team Members	Helpline, Case Managers, Employment and Technology Positions
Partnerships	DD Council, B3, SDE Lifespan Committee, SDE presentations, Transition Community of Practice, Aging Livable Communities Partnership, Assistive Technology Projects, Employment Partnerships	Continued expansion with groups across the lifespan, especially local-based community groups
Funding	Respite, Family Grants	*New providers, system improvements, new funding where possible
Policies & Procedures	PWCL Waiver Service	*CoP Committees Sustainability Goals
Training	Academy Project	Trainings for Families
Quality	LEAN, ADP/Compass Project- Navigating Across the Lifespan	NCI, QSR

A GOOD LIFE



What We've Learned Through the Supporting Families Community of Practice

LEARNING	BARRIERS	What we hope will change...
<p>Caring For and Caring About “Caring about” people with ID/DD is the responsibility of all. It is not just a family concern.</p>	<p>Separating “caring about” and “caring for” increases the probability of abuse & neglect</p>	<p>Our communities become caring places for all. We care for ourselves and we care for one another.</p>



As you look at the work of the committees consider:

- **GOALS**: What are the goals of this committee for the next two years? What are the planned activities of this committee? Can you -contribute to the implementation of these goals and activities?
- **LEARNING MOMENTS**: What did the committee learn in the first year? Did any of the learning moments provide ideas on how you can live your life/or do you work differently?

As you look at the work of the committees consider:

- **BEST PRACTICES:** What did the committee learn about best practices that they now want to share with others? How can you help share this information?
- **POLICY CHANGES:** What are the critical policy changes that this committee may have identified? Can you help with this?



Sharon Lewis is the Principal Deputy Administrator at the Administration for Community Living (ACL)

From March 2010 to April 2012, Ms Lewis served as the Commissioner of the Administration on Developmental Disabilities. Prior to her appointment as Commissioner, she served as the Senior Disability Policy Advisor to U.S. House Committee on Education & Labor, advising members of the Committee on legislative strategy and disability-related policy issues in education, employment and healthcare, and as a Kennedy Public Policy Fellow for U.S. Senate Subcommittee on Children & Families.

Sharon is the recipient of numerous awards, including the 2010 Distinguished Leadership in National Disability Policy Award and the Consortium for Citizens with Disabilities Chairman's Award. In Oregon, Sharon worked on public policy for the Oregon Developmental Disabilities Coalition and for The ARC. She served as co-chair of the Oregon Family Action Coalition Team, founded DisabilityCompass.org and managed the Oregon Partners in Policymaking Program. Sharon is a parent to three daughters, including one with a disability.

CHARTING the life course

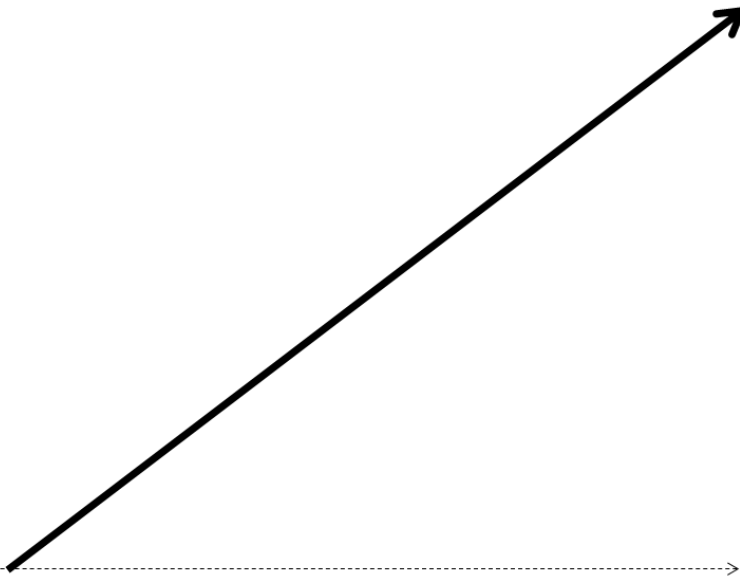


Life Trajectory Worksheet: Individual

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

VISION for a GOOD LIFE

What I DON'T Want



MAY 2014

A Good Life

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CHARTING the life course

Life Trajectory Worksheet: Family

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.

VISION for a GOOD LIFE

What I DON'T Want

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Developing A Vision

CHARTING the life course



Tool for Developing a Vision - Family

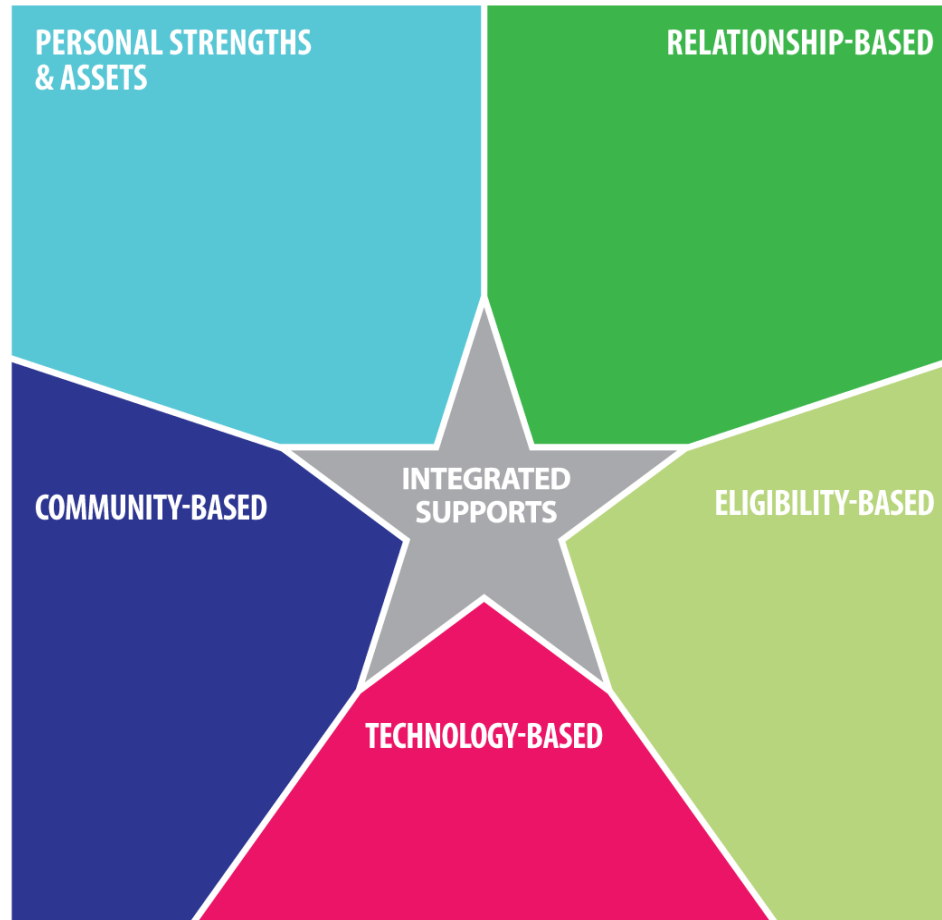
Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help families of all ages—those with a very young child, an adult or somewhere in between, start to think about a vision for how their family member will live their life as an adult.

LIFE DOMAIN	My Vision for My Family Member's Future	rank	Current Situation/Things to Work On	rank
 Daily Life Employment	What do I think my child will do during the day in his/her adult life?			
 Community Living	Where and with whom do I think my child will live in his/her adult life?			
 Social & Spirituality	How will my child connect with spiritual and leisure activities; have friendships and relationships in his/her adult life?			
 Healthy Living	How will my child live a healthy lifestyle and manage health care supports in his/her adult life?			
 Safety & Security	How will I ensure the safety of my child from financial, emotional, physical or sexual harm in his/her adult life?			
 Citizenship & Advocacy	How can I make sure my child has valued roles and responsibilities, and has control of how his/her own life is lived as an adult?			
 Supports for Family	What will our family need to help support my child to live a quality life as an adult?			
 Supports & Services	How will my child be supported in his/her adult life to lead the kind of life he/she wants as independently as possible?			

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CT DDS NEW MODEL SERVICES

Integrated Supports









CHARTING the life course



Tool for Planning Supports and Services: Life Domains

Once you have determined specifics for your good life vision in the life domains, this tool will help you think about the integrated supports and services that will help you get there. This might include things that are already in place as well as things that you would like to work on putting into place.

LIFE DOMAIN	Relationship Based Supports	Technology	Community Resources	Eligibility Based Supports
 Daily Life Employment				
 Community Living				
 Social & Spirituality				
 Healthy Living				













Uncharted Possibilities

CHARTING the life course



Services and supports have been around for a long time. What might have been great 30 years ago, may not work for today's vision of a quality life in the community. This tool is to help individuals and families look at a variety of kinds of supports, some of which are traditional or historic and no longer preferred by many (*charted*), some that are known and tried, but not necessarily the norm (*slightly charted*), and others that are new or unfamiliar to individuals, families and professionals, but that are more likely to lead to inclusive lives (*uncharted*).

	 Daily Life Employment	 Community Living	 Social & Spirituality	 Healthy Living	 Safety & Security	 Citizenship & Advocacy	 Supports for Family Unit	 Supports & Services
INNOVATIVE SUPPORT	New ideas; things that someone has tried, and you replicate or adapt for your own needs; things that haven't been thought of yet or tried.							
UN-CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Micro-enterprises • Careers • Competitive employment • Inclusive college experience 	<ul style="list-style-type: none"> • Co-op • Adapted living space • Environmental technology • Shared living • Public transportation 	<ul style="list-style-type: none"> • Friendships • Dating/relationships • Parks and Recreation • Inclusive faith community • Service/social club/groups 	<ul style="list-style-type: none"> • Individual gym membership • Community Health Centers • Health fairs • Family practice providers 	<ul style="list-style-type: none"> • Limited/joint bank account, automatic bill pay, personal contract or agency agreement, Personal safety devices 	<ul style="list-style-type: none"> • Voting • Neighborhood group or organization • Self-Advocacy • Visiting your legislator 	<ul style="list-style-type: none"> • Social Media • Technology • Blogs • Family & friends 	<ul style="list-style-type: none"> • Exchange networks • Time banks • Human service co-ops • General education
SLIGHTLY CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Supported employment • Work crews or enclaves • Job coaches • Volunteering • Special college programs 	<ul style="list-style-type: none"> • Independent Supported Living (ISL) • Home of Your Own (program) • Independent Living Center 	<ul style="list-style-type: none"> • Special Olympics • Special passes • Social skills classes 	<ul style="list-style-type: none"> • In-home or community based therapies • Family member or school staff implement therapy • Special Olympics Healthy Communities 	<ul style="list-style-type: none"> • Limited guardianship • Remote monitoring • Special Needs Trust • Power of Attorney 	<ul style="list-style-type: none"> • People First/SABE • Disability Rights Day at the Capitol • Project STIR 	<ul style="list-style-type: none"> • Peer Support/P2P • Face-to-face local support groups • Online Support Groups • Sib-shops 	<ul style="list-style-type: none"> • Self-Directed Supports • \$\$ follows the person • Technology/remote monitoring
CHARTED SERVICES AND SUPPORT	<ul style="list-style-type: none"> • Sheltered workshops • Day habilitation 	<ul style="list-style-type: none"> • Institutions • Intermediate Care Facility (ICF) • Group Homes 	<ul style="list-style-type: none"> • Separate or special church service • Special group outings & activities 	<ul style="list-style-type: none"> • Center-based therapies (PT, OT, Speech, etc) • Special or institutional medical care 	<ul style="list-style-type: none"> • Full guardianship • 24 hour supervision 	<ul style="list-style-type: none"> • Paid advocate or having someone else advocate on your behalf 	<ul style="list-style-type: none"> • Institution or center based support group • Intensive all-day parent training • Disability specific groups 	<ul style="list-style-type: none"> • Systems supports • Provider and agency staff

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Guiding Questions for Case Studies

- 1. How can you use the Life Course materials to help create a positive vision of the future for this family?**
- 2. What ideas do you have to help this family develop an integrated plan of supports?**
 - Building on Their Strengths and Assets**
 - Developing Relationship Based Supports**
 - Using Technology**
 - Creating Community- Based Supports**
 - Finding Eligibility- Based Supports**
- 3. What other unchartered possibilities may this family want to explore?**
- 4. Did the Life Course materials change the way you thought about how to provide supports for this family? In what ways?**

B3 Case Study - Matiu

Matiu was born Deaf. At the time of his birth, his parents didn't know anyone who was Deaf and had few experiences being around people who had a disability. His parents, both of whom use Spanish as their primary language, knew that they needed to get more information, but were reluctant to talk to others about their son's disability.

Matiu's parents also have concerns that he may be developmentally delayed and are unsure of where to get help. They hope that someday their son will be an accepted and valued part of their community.

Early Childhood (age 3-8)

Case Study - Anne

(Anne is a 4 year old who lives with her mother and father and big sister Jane in a typical suburban community.) One April morning, after eight months of assessment, observations and countless appointments we were told that our physically perfect, attractive four-year-old daughter was 'handicapped'; she was diagnosed as having autism. The grief was almost all consuming and our lives changed forever. Our daughter's inability to understand people and language causes her constant stress. She copes by organizing her life into structured routines that only she understands. Just coping is difficult for our family and for her. This has been compounded by the difficulties of the 'system' and an unaccepting community. All we hope for is that our daughter will be an accepted, valued member of our community who has the opportunity to contribute and participate.

Middle School Case Study

Kevin

- **Kevin** is a 14 year old young man with significant intellectual disabilities who is attending his neighborhood middle school. He receives daily instruction in Literacy (reading, writing, and communication), Math, and Science. Kevin also is involved in vocational and daily living skill training. His coursework is delivered in individual and small group settings in the special education classroom except for Digital Communications (a general education Career Technical Course) which he has taken (using a modified curriculum) with the assistance of a one-on-one instructional assistant. Kevin also participates in a school-based enterprise through the Occupational Course of Study (a state endorsed curriculum for students with special needs leading to a high school diploma) and an on-campus work placement in the school library. Kevin and his family plan for him to stay in the public schools until he ages out at age 21. Kevin lives at home with mother, step-father, 11 year old sister, and a great aunt that helps with his care. Kevin also has one older brother who is in college.

High School Case Study

Paul

Paul is a sixteen year African American male who has an intellectual disability and who experiences mood swings and hears voices that other people don't understand.

Paul's family lives in a small town, where gossip spreads like wildfire. He often stays home alone playing video games and has little confidence about his future. Paul really wants to work. He would like to start his own business someday. Paul lives with his mother and with his younger sister, who has a learning disability. His family is very involved in their church and they get a lot of natural support from this community.

Adult Case Study

Janie

Jane is 23 years old and has Down Syndrome. She attended public high school, where she met her live-in boyfriend Sam. She lives in a large metropolitan area in a neighborhood that used to be considered respectable. However, recently there has been a lot of crime reported in the neighborhood.

Jane's Voice: "After having my baby and returning to the ward, people reacted to me really differently. Some people were very supportive. Others assumed that I was just a visitor from another ward or were amazed that I had actually been able to have my own baby. Some mothers I talked to even overheard comments like, 'I think it's disgusting, letting "them" have babies. The nurse told me they have to give me a test to see if I can keep my baby. I want to bring my baby home and take care of her. I know I will need some help, but I am going to try and be the best mom I can be."

Aging Case Study

Margaret

Margaret is 60 years old. She lives in a group home with four other people who are younger than her. She has lived in the home for the last twenty years. She wants to remain in the home with people who know and care about her. She has very little contact with her family and no friends outside of the people with whom she lives.

Four months ago Margaret fell and was knocked out. From that day onward she has been a different person. She is often disoriented and has difficulty caring for herself. She is often in pain so is not in the best of moods. Her health is declining and the agency is not sure what to do next.

Thank you!