

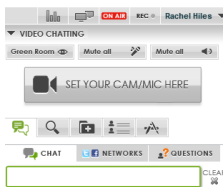
BROWN BAG LUNCH WEBINAR

September 28, 2011

Uncharted Waters:
Moving Beyond What We Know as Family Support



How to Participate



CHAT – To communicate with the hosts or the other participants, you can type your comments in the CHAT area below

NETWORKS – To share this webinar on Facebook or Twitter, you can click your favorite one and invite people to join in!

QUESTIONS – If at any time you have a question, you can type it in this box and we will answer it when questions are taken



How to Participate

FULL SCREEN MODE

To enter full screen mode, click on the icon in the corner of the webinar that says "Full Screen." You can quickly exit Full Screen Mode by hitting the ESCAPE key on your keyboard.



Please note: If you are in full screen mode, you will not be able to view the tabs you need to interact with us.



Voice line

- The voice line for today's call is (800) 444-8652.
- You can dial in with meeting ID: **9281200**.



Uncharted Waters:
*Moving Beyond What We Know as
 Family Support*

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 September 28, 2011

Family Support and My Family



Charting the Waters of Family Support

Charted	Slightly Charted	Uncharted
<ul style="list-style-type: none"> • Removes value judgments and blame • Not a continuum, but current or historical options <ul style="list-style-type: none"> • Does not imply a state is or isn't doing • 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"



HISTORY OF FAMILY SUPPORT

Charting a New Family Support

<i>Chartered</i>	<i>Slightly Chartered</i>	<i>Uncharted</i>
Programs provided by services system to person:	Services provided in the family home:	Infrastructure that supports living in the community:
Case-management	Person-centered planning	Instrumental Services
Providers	Cash-Subsidies	Emotional and Self-Efficacy Support
Group homes	Respite	Information and Training
Independent Supported Living	Home Modification	

Charting a New Family Support

<i>Chartered</i>	<i>New Charter</i>
Defined by service system or eligibility	Defined by self-advocates, families, the disability service system, and other stakeholders
Caregiver or parent	Family is defined functionally; inclusive of siblings, parents with disabilities, grandparents
Tension between self-advocacy and family support	Family support enhances opportunities for self-advocacy and self-determination
Crisis, immediate response	Preventative, long-term planning
Supporting caregiver in order to decrease demand on long-term services	Create a quality of life for person with ID/DD and their family

Beliefs of State Service Systems

People with ID/DD have a right to:

- Be safe in their homes and communities;
- Be treated with respect and dignity;
- Be independent and make individual choices;
- Participate in family and community life; and
- Have opportunities to work and contribute to their community.

ELEMENTS OF FAMILY SUPPORT

Objective of Family Support

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.**

-working definition from National Agenda on Family Support Conference, 2011.

New Charter for Family Support

Family Support is:
 A value-based approach to providing services to families and their family member with ID/DD:

- driven by the family and family member with ID/DD
 - recognizes the family as a system
- focuses on the strengths, capacity and diversity of family
- Builds on network of all family members and community

Instrumental Supports:
Day-to-Day Needs

Emotional Supports:
Mental Health and Self-efficacy

Information and Training Supports:
Knowledge and skills



Family Support Value-based Approach		
<p>Instrumental Supports: <i>Day-to-Day Needs</i></p> <ul style="list-style-type: none"> • Respite/Childcare • Adaptive equipment • Home modifications • Financial assistance • Service Coordination • Cash Subsidies • Person/family-centered planning 	<p>Emotional Supports: <i>Mental Health and Self-efficacy</i></p>	<p>Information and Training Supports: <i>Knowledge and Skills</i></p>



Family Support Value-based Approach		
<p>Instrumental Supports: <i>Day-to-Day Needs</i></p>	<p>Emotional Supports: <i>Mental Health and Self-efficacy</i></p> <ul style="list-style-type: none"> • Parent-to-Parent Support • Self-advocacy organizations • Sib-shops • Support Groups • Professional Counseling • Non-disability community support 	<p>Information and Training Supports: <i>Knowledge and Skills</i></p>



Family Support Value-based Approach		
<p>Instrumental Supports: <i>Day-to-Day Needs</i></p>	<p>Emotional Supports: <i>Mental Health and Self-efficacy</i></p>	<p>Information and Training Supports: <i>Knowledge and Skills</i></p> <ul style="list-style-type: none"> • Information on disability • Knowledge about best practices and values • Skills to navigate and access services • Ability to advocate for services and policy change

Information and Training Support (Knowledge and Skills)		
	Charted	Uncharted
Information on disability	<i>Specific diagnosis and interventions, therapies, and services</i>	<i>Personal stories of hope, possibilities, and opportunities</i>
Knowledge about best practices, values, and philosophy	<ul style="list-style-type: none"> • Housing • Education • Employment • Sexuality • Health care • Early childhood • Recreation 	<ul style="list-style-type: none"> • Inclusion and integration • Productivity and meaningful life • Self-Determination • Social Capital • Natural Supports • Family/person- centered thinking

Information and Training Support (Knowledge and Skills)		
	Charted	Uncharted
Skills to navigate and access services	<i>Available services and eligibility criteria</i>	<i>Understanding and ability to navigate and access different supports within and outside of disability services</i>
Ability to advocate for services and policy change	<i>Understand rights and responsibilities</i>	<i>Enhance skills to make a change for family and for services and systems</i>

**FAMILY SUPPORT AND
DISABILITY SERVICES**

FS Impact on Demand for Services

Family support

- Is BIGGER than the service system, utilizes resources within and outside of
- Can help to CHANGE EXPECTATIONS of role and responsibility of service system, themselves and their community
- Helps families PLAN FOR POSSIBILITIES and dreams before crisis, life-transitions and future
- Potential to LESSEN THE FREQUENCY AND LONG-TERM NATURE of crisis services.

Impact of Family Support on Services			
	Charted	Slightly Charted	Uncharted
Housing	<ul style="list-style-type: none"> • Institutions • ICF • Group Homes 	<ul style="list-style-type: none"> • Independent Supported Living • Home of Your Own 	<ul style="list-style-type: none"> • Shared Living • Co-op • Planned Living Space in Home
Meaningful Day	<ul style="list-style-type: none"> • Sheltered Workshops • Day Habilitation 	<ul style="list-style-type: none"> • Supported Employment • Volunteerism 	<ul style="list-style-type: none"> • Micro-enterprises • Careers
Direct Care and Support	<ul style="list-style-type: none"> • Staff of Provider 	<ul style="list-style-type: none"> • Family/Self-directed services • Respite • Natural supports • Micro-boards 	<ul style="list-style-type: none"> • Exchange networks • Time banks • Human service cooperatives

Impact of Family Support on Services			
	Charted	Slightly Charted	Uncharted
Planning and Coordination	<ul style="list-style-type: none"> • Coordination of state services by a case-manager based on current needs 	<ul style="list-style-type: none"> • Facilitated outside of system • MAPS, Futures Planning, Person-centered planning • Special Needs Trusts 	<ul style="list-style-type: none"> • Long-term planning inside/outside of system • Financial security and planning • Life coach • Family facilitated • Support Brokers
Safety	<ul style="list-style-type: none"> • Guardianship 	<ul style="list-style-type: none"> • Alternatives to Guardianship • Self-advocacy skills 	<ul style="list-style-type: none"> • Self-determination • Social Capital

Eric's Uncharted Life



NOW WHAT??

Re-charter Family Support in Your State

- "Don't explore on your own": Share problem-solving and responsibility with stakeholders across the lifecourse and outside of state service system
- Discover your states existing "map of family support" (services, policies, organizations)
- Identify strategies and efforts to assist families to "navigate" supports
- Infuse family support approach and practices into how all families are served.

Explore and Join Innovative Conversations and Solutions

- **National Agenda on Family Support**
 - Wingspread Conference of national family support leaders held in March to generate recommendations for state and federal policy on family support, including the reauthorization of the Developmental Disabilities Act.
 - www.familysupportagenda.org
 - Join listserv on website to learn about and support agenda

Explore and Join Innovative Conversations and Solutions

Findings from surveys:

- **The ARC FINDS Survey 2010:** 5800 responses to a survey to gain a greater understanding about what services are available, what gaps exist and what new supports are needed. Report available June 2011.
- **PACER Center Family Support Survey 2010:** Report summarizes the results of a 2010 national internet survey of 2,416 parents or relatives of children and youth ages 11 years to 39 years with disabilities .

Increase awareness of Family Support Policy and Initiatives

Such as:

- **Lifespan Respite Act**
- **Aging and Disability Resource Centers**
- **National Family Caregiver Support Program**
- **Older Americans Act**
- **CAPTA Child Abuse, Prevention & Treatment Act**
- **DD Act, Title II: Family Support**

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

-unknown



Contact Information

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Questions?????



Survey

Please take the time to visit our surveymonkey evaluation of this webinar and tell us what you thought!

<http://surveymonkey.com/s/unchartedwaters>



Special Thanks

- MODHSS Bureau of Special Healthcare Needs
- Miller County Health Department
- Missouri Planning Council for Developmental Disabilities
- DMH Regional Offices and Family Support Coordinators



Next Month's Webinar

**Moving Along the Timeline:
Understanding the Past, Present &
Future of Disability**

October 26, 2011 at 12:00pm

October is Disability History Awareness Month
in Missouri!

Learn how the past of disability impacts the policies, services,
& supports of today.



Next Month's Webinar

Contact the
**Missouri Family-to-Family Resource
Center**

800-444-0821

<http://mofamilytofamily.org>



**UMKC-Institute for Human
Development**

<http://www.ihd.umkc.edu>