

2011 AMCHP and Family Voices National Conferences

WORKING TOGETHER TO IMPROVE MATERNAL AND CHILD HEALTH

February 12-15, 2011 • Omni Shoreham Hotel • Washington, DC • amchp.org/conference

Building a Statewide Family- Driven Navigator Network for Families of Children with Developmental Disabilities and Special Health Care Needs

Child Health Specialty Clinics (Iowa Title V Program for CYSHCN)

- Debra Waldron, M.D., MPH – Director
- Barbara Khal, MA, Director, Division of Public Health
- Rachell Swanson-Holm, Parent and Project Director of Family Support 360
- Erica Zito, Parent and Project Director of F2F Health Info Center



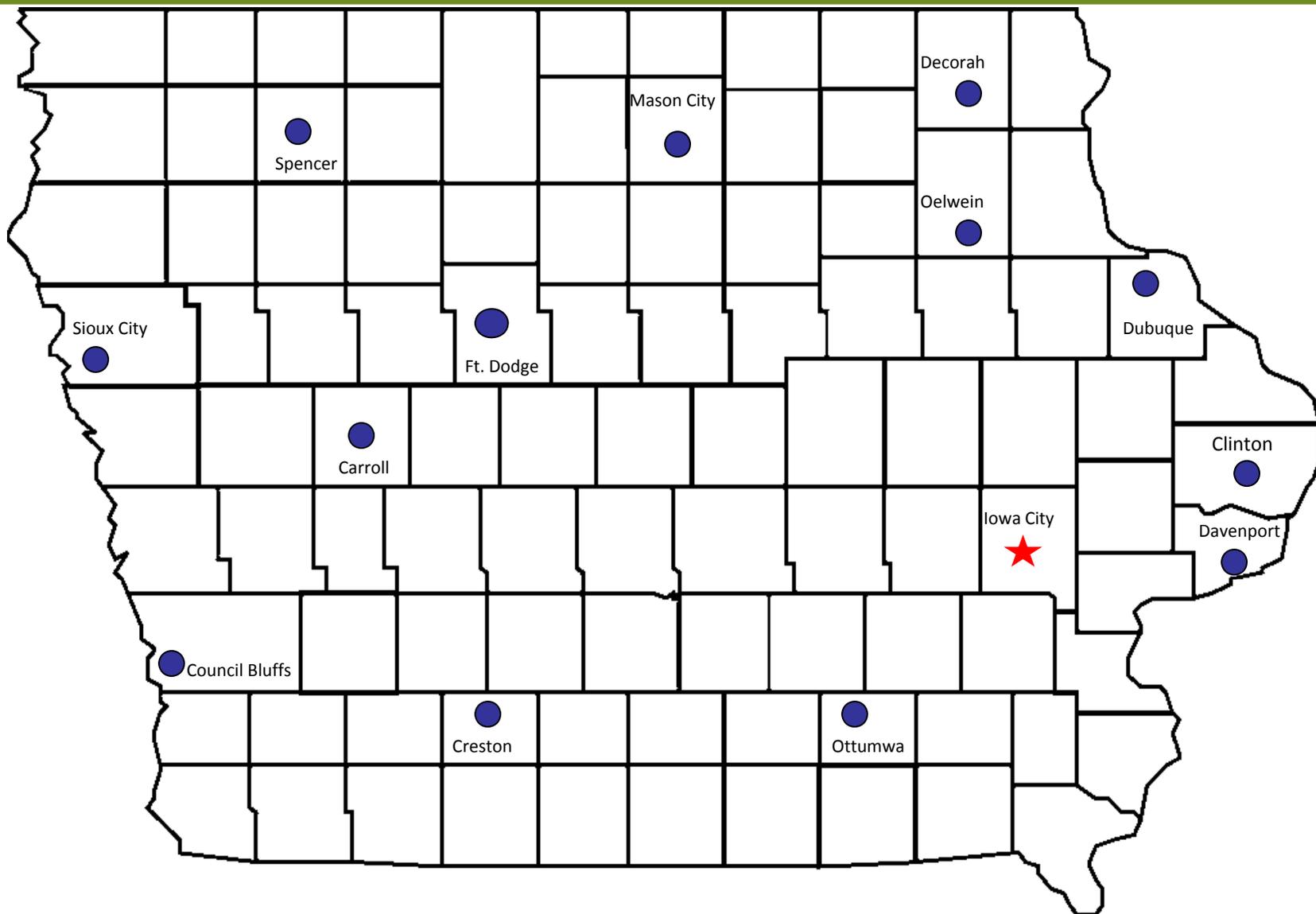
Climate of Family Support in Iowa before F2F Iowa was created

From the 2006 National CYSHCN Survey, Iowa families reported that:

- 25% did not receive family-centered care;
- 19% had financial problems due to their CYSHCN's condition;
- 6% spent at least 11 hours per week providing or coordinating their child's care;
- 17% have had to cut back or stop working due to their child's condition;
- 35% did not feel they were partners in decision-making at all levels regarding their child's health care and were not satisfied with services received;
- 43% did not have a medical home in which their CYSHCN received ongoing, coordinated, comprehensive care; and
- 53% who have teens with special health care needs did not receive services necessary for successful transition.

Families reported problems of inconsistent, inadequate, and non-evidence-based information.

Child Health Specialty Clinics Regional Centers July 2010



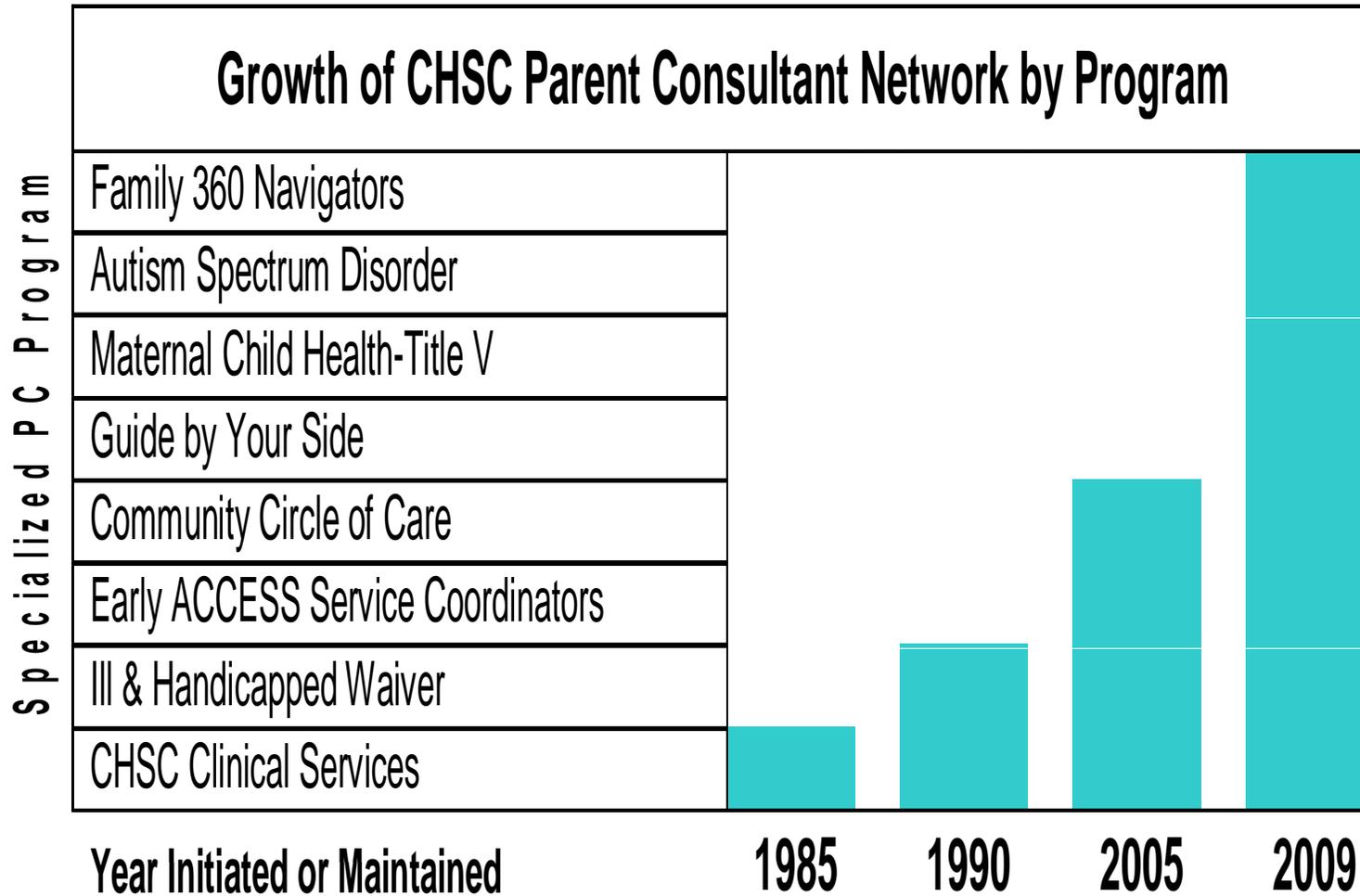
● Regional Centers

★ Central Office

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Parent Consultants



Child Health Specialty Clinics Regional Centers July 2010

Department of Education – Parent Educators

Decorah

Magellan Behavioral Health

Spencer

Private Family Support/Advocacy Groups

Oelwein

Sioux City

Ft. Dodge

Dubuque

Carroll

Department of Education – Part C, IDEA – Service Coordinators

Iowa City

Davenport

Department of Human Services – Children at Home Navigators

Council Bluffs

Creston

Ottumwa

Ill and Handicapped Waiver and other waivers – Case Workers

Regional Centers

Central Office

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- No unified family-directed statewide vision
- Multiple family support groups but lack of communication between the groups, medical homes, and other providers
- No shared definition of “family support”/”care coordination”
- Variance in quality of family support from group to group and geographic location
- Technology was not available for easy access to information
- Iowa had no significant data to show that family support made a difference
- Families had no easy point of entry into the world of family support
- Many families were not supported



Ann – Center for Disabilities and Development

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Family to Family Iowa is a combination of the two federal funding sources



Family to Family
IOWA

*The network of supports and services
for Iowans with special needs*

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Family Support 360

**Administration on Developmental Disabilities,
Administration for Children and Families, U.S. Dept of
Health and Human Services, Family Support-360 grant
number 90DN0260, awarded October 2009 for five
years.**

- Support families in accessing services and supports through system navigation as a part of developing a family-driven statewide system of care for children in Iowa.
- Assist families making informed choices (options available supports/services) through direct family support and navigation.
- Enhance the competencies of staff working with families to provide system navigation.
- Enhance a web-based resource to assure Iowa's network of family navigators all have access to the same resources needed to help families make informed choices.

Family to Family Health Information Center

US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs, Iowa Family to Family Health Information Center, HRSA 1 H84 MC12899-01, awarded June 2009 for three years.

- To develop a cohesive, coordinated, culturally competent statewide network of family mentors/educators to serve families with CYSHCN.
- To assist families of CYSHCN in making informed choices about health care.
- To support development and replication of successful models of family/professional partnership at all levels of decision-making.

Family to Family Iowa is a combination of the two federal funding sources



Family to Family
IOWA

*The network of supports and services
for Iowans with special needs*

Family to Family Iowa Family Governance Council

The Arc of Iowa
ASK- Parent Training and Information Center
Autism Society of Iowa
Brain Injury Association of Iowa
Center for Disabilities and Development
CHADD of Iowa
Child Health Specialty Clinics
Community Circle of Care
Disability Resource Library
Epilepsy Foundation North/Central Illinois Iowa & Nebraska
Family Voices of Iowa
Hands & Voices Guide By Your Side
Hawkeye Area Down Syndrome Association
Iowa Department of Education Parent Educator Connection
Iowa Department of Human Services
Iowa Developmental Disabilities Council
Iowa Federation of Families for Children's Mental Health
Iowa Foster and Adoptive Parents Association
Iowa Braille and Sight Saving School
Magellan Consumer/Family Advocate
NAMI Iowa
Prader-Willi Society
Project Literacy Iowa



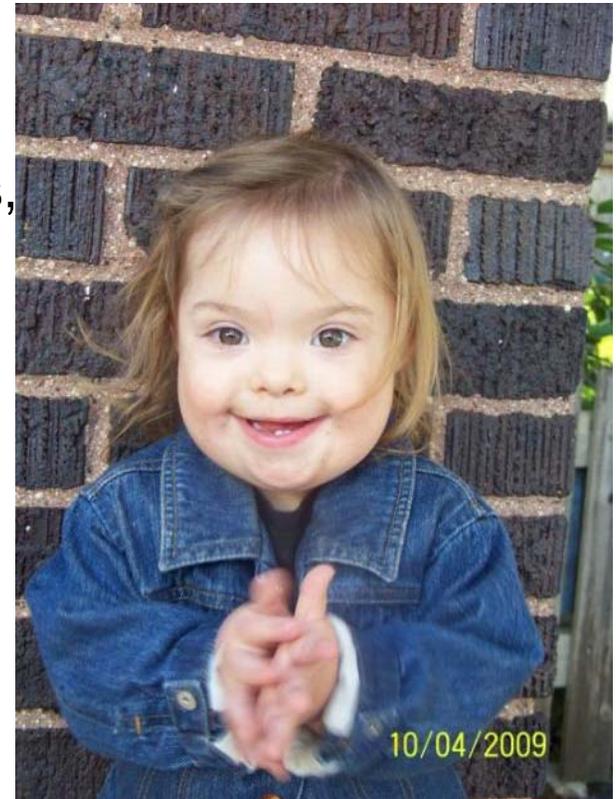
Deb – Parent Education

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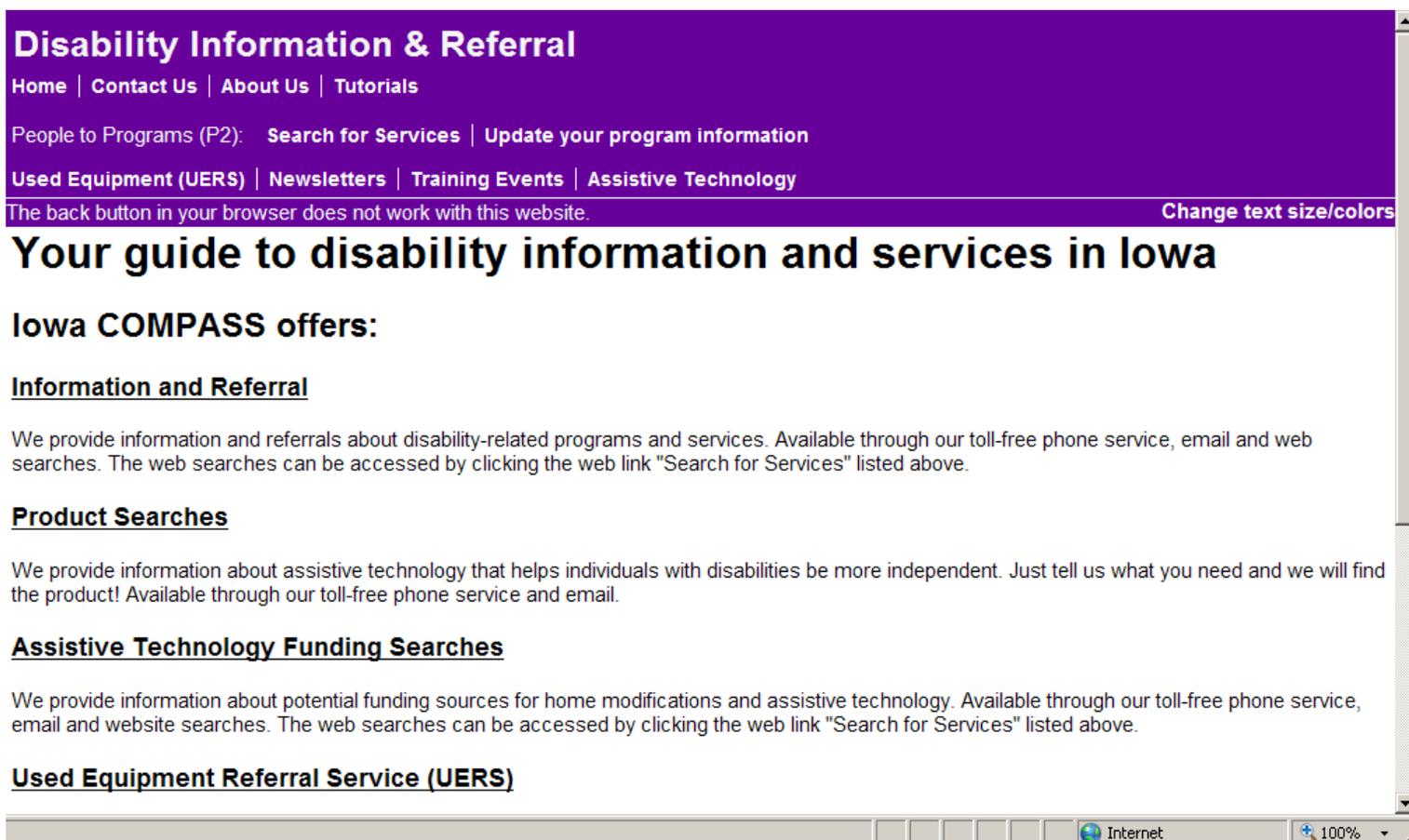
Benefits of merging two projects

- We hope to create a “one-stop shop” for families.
- We can reach more families.
- We are decreasing fragmentation through agency and families networking.
- We are providing the same core training across the state for parents providing Family Support.
- We can share resources, such as training dollars, training manual, intake/assessment and the website.
- We have more people “at the table” to share more ideas.
- Communication is improving among agencies locally, statewide and nationally.
- We are collecting impact data together, which is more likely to show the value of Family Support.



Iowa COMPASS – Disability Info and Referral

Partnering with Family to Family Iowa



Disability Information & Referral

[Home](#) | [Contact Us](#) | [About Us](#) | [Tutorials](#)

People to Programs (P2): [Search for Services](#) | [Update your program information](#)

[Used Equipment \(UERS\)](#) | [Newsletters](#) | [Training Events](#) | [Assistive Technology](#)

The back button in your browser does not work with this website. [Change text size/colors](#)

Your guide to disability information and services in Iowa

Iowa COMPASS offers:

Information and Referral

We provide information and referrals about disability-related programs and services. Available through our toll-free phone service, email and web searches. The web searches can be accessed by clicking the web link "Search for Services" listed above.

Product Searches

We provide information about assistive technology that helps individuals with disabilities be more independent. Just tell us what you need and we will find the product! Available through our toll-free phone service and email.

Assistive Technology Funding Searches

We provide information about potential funding sources for home modifications and assistive technology. Available through our toll-free phone service, email and website searches. The web searches can be accessed by clicking the web link "Search for Services" listed above.

Used Equipment Referral Service (UERS)

Internet 100%

Katie - COMPASS

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Family Navigator Training Manual

Pre-requisites

- General organization
- Group process

Core curriculum

- Confidentiality
- Relationship building
- Recovery and resiliency
- Conflict resolution
- Empowerment strategies
- Education issues
- Special health care
- Cultural and linguistic competencies
- Resources and referral
- Department of Human Services (DHS)
- Juvenile Court

Supplemental requirements

- DHS OASIS
- Certification in Human Subject Protection
- Guardianship and conservatorship
- Emergency preparedness
- Mandatory reporting
- Impact data collection

Martha – Network Navigator

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Family to Family Iowa Wiki

A temporary place to connect and share resources

The screenshot shows a Windows Internet Explorer browser window displaying the home page of the Family to Family Iowa Wiki. The browser's address bar shows the URL <http://wiki.uiowa.edu/display/F2FHIC/home>. The page title is "Home - Family to Family Iowa - ITS Wiki Service".

The page content includes a search bar, a navigation menu on the left with items like "Data and Reporting", "F2F Presentations", and "Family Support Conference", and a main content area with the following text:

Home
Added by Daniel Dirks, last edited by Vicki Hunting on Jul 22, 2010 (view change)

This is the home of **Family to Family Iowa**. The network for supports and services for Iowans with special needs.

This group is made up of family support stakeholder groups from around Iowa to help families find the services and supports for their children with special healthcare needs. It is supported by 2 federal grants, HRSA/MCHB Family to Family Health Information Center (F2F HIC) to CHSC in June and Family Support 360 (FS360) grant funded by US Dept of HHS-ACF Admin on Developmental Disabilities awarded to DHS in 2009.

To help you on your way, we've inserted some of our favourite macros on this home page. As you start creating pages, adding news items and commenting you'll see the macros below fill up with all the activity in your space.

Recently Updated

Document Name	Attached by	Date
Presentations 1st Quarter.doc	Rachell Swanson-Holm	Jan 10
Quarterly Report to DHS 10-1-2010-12-31-2010.doc	Rachell Swanson-Holm	Jan 10
Learn the Signs Act Early.doc	Ellisa Wendi	Jan 07
Autism Society of Iowa (ASI).xls	Rachell Swanson-Holm	Jan 02
Brain Injury Association of Iowa Training Tracking Log.xlsx	Rachell Swanson-Holm	Jan 02
Epilepsy Foundation North Central Illinois, Iowa, Nebraska.xls	Rachell Swanson-Holm	Jan 02
Guide By Your Side Training Tracking Log.xls	Rachell Swanson-Holm	Jan 02
Ask Resource Center Training Tracking Log.xls	Rachell Swanson-Holm	Jan 02
Family Voices Training Tracking Log.xlsx	Rachell Swanson-Holm	Jan 02
Hawkeye Area Down Syndrome Association Training Tracking Log.xls	Rachell Swanson-Holm	Jan 02
Iowa Federation of Families Training Tracking Log.xls	Rachell Swanson-Holm	Jan 02

Navigate space

- Data and Reporting
- F2F Presentations
- Family Support Conference
- FGC Stakeholders
- FS360 Grant Info
- Ia F2F FGC Contact List
- Logo Files
- Meeting Notes
- Navigator Training Tracking
- Resources (Family Voices, other org links, info, etc.)
- Speakers Bureau
- Tools for Assessing Family Needs
- Training
- Work Plans and SOW

At the bottom of the page, it says "Powered by Atlassian Confluence 3.4.5, the Enterprise Wiki | Report a bug | Atlassian News".

Family to Family Iowa Website

The network of supports and services for Iowans with special needs.

Phone (855) 275-4444 Fax (641) 782-9519 [Contact Us Online](#)

Family to Family IOWA

HOME ABOUT US OUR SERVICES RESOURCES CONTACT US

News & Information
New Resources Available
New resources are now online within our [Help for Parents](#) section.

Conference Registration
Register now for the fifth annual conference. You can [Register right on our website](#) to get signed up. Registration ends February 5th.

Need Help?
We can help. We've been working to compile a comprehensive glossary of terms and definitions to help you understand all the information. Your navigator will also offer experience and guidance on the way. [Click here to access our resources.](#)

FIND SOURCES OF SUPPORT FOR A CHILD WITH SPECIAL NEEDS
Sometimes simple advice or direction, mixed with experience, makes a world of difference.
[Click for Resources](#)

Welcome Family to Family Iowa
Family to Family Iowa is a statewide network of navigators who provide comprehensive and casual assistance to families of children with special health care needs (developmental, behavioral, emotional, physical.) **We can:**

- Help families navigate the supports and services available for their child with special needs.
- Help families navigate the supports and services for other members of the family. It's not just about the child with special health care needs!
- Help families develop skills to advocate for themselves through trainings and more.

"Family to Family Iowa has helped our family grow and engage life like never before. Thank you so much for helping us!"

John S.
Des Moines, IA

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The network of supports and services for Iowans with special needs.

Child Health Specialty Clinics
100 Hawkins Drive Iowa City, IA 52242
Phone (855) 275-4444 Fax (641) 782-9519

Linking the network together

More Marketing

Do you sometimes feel frustrated and all alone?
Are the worries of parenting a child with special needs overwhelming you?
Do you need help finding resources in your area?
Would you like to talk to someone who has walked in your shoes?

Contact *Family to Family Iowa* for help.
The network of supports and services for Iowans with special needs



One of the most meaningful sources of support is another parent or family member who has lived with a child with special needs. Sometimes simply having someone to listen makes a world of difference.

No matter the disability or health concern, Family to Family Iowa can help by connecting you with other parents with similar experiences. So call toll free **866-219-9119, ext. 2** to get started!



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Family to Family Iowa is a statewide network of Navigators who provide assistance to families of children with special needs (developmental, behavioral, emotional, physical) at no cost to families.

We can:

- Help families navigate the supports and services available for their child.
- Help families navigate the supports and services for other family members. It's not just about the child with special needs!
- Help families develop self-advocacy skills through trainings and more.

F2F current consists of Family to Family Iowa Family Governance Council consists of: The Arc of Iowa; ASMParent Training and Information Center; Autism Society of Iowa; Brain Injury Association of Iowa; The Center for Disabilities and Development; Iowa's Center for Excellence on Developmental Disabilities (UCEDD); CHADD of Iowa; Child Health Specialty Clinics; Community Circle of Care; Disability Resource Library; Epilepsy Foundation North Central Illinois Iowa & Nebraska; Family Voices of Iowa; Hands & Voices Guide By Your Side; Hawkeye Area Down Syndrome Association; Iowa Braille and Sight Saving School Statewide System for Vision Services; Iowa Department of Education Parent & Educator Connection; Iowa Department of Human Services; Iowa Developmental Disabilities Council; Iowa Federation of Families for Children's Mental Health; Iowa Foster and Adoptive Parents Association; Iowa Hands & Voices; Magellan Consumer/Family Advocate; NAMI Iowa; Prader-Willi Society; Project Literacy Iowa and other family-centered organizations. We welcome new partners.

F2F is supported by: US Department of Health and Human Services, Health Resources and Services Administration, Maternal and Child Health Bureau, Division of Services for Children with Special Health Care Needs, Iowa Family to Family Health Information Center, HRSA 1 H84 MC12899-01 and Administration on Developmental Disabilities, Administration for Children and Families, U.S. Dept of Health and Human Services, Family Support-360 grant number 90DN0260.

www.familytofamilyiowa.org

Call toll free: **866-219-9119, ext. 2**; Fax: **319-356-3715**

e-mail address: Info@familytofamilyiowa.org



Family to Family Iowa
Child Health Specialty Clinics
100 Hawkins Drive, Room 247 CDD
Iowa City, IA 52242

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Challenges . . .

- Training Navigators – 40-60 hours is a time and financial burden for many, especially small agencies
- Keeping everyone informed/communication
- Assuring confidentiality across agencies
- Involving representation from diverse groups



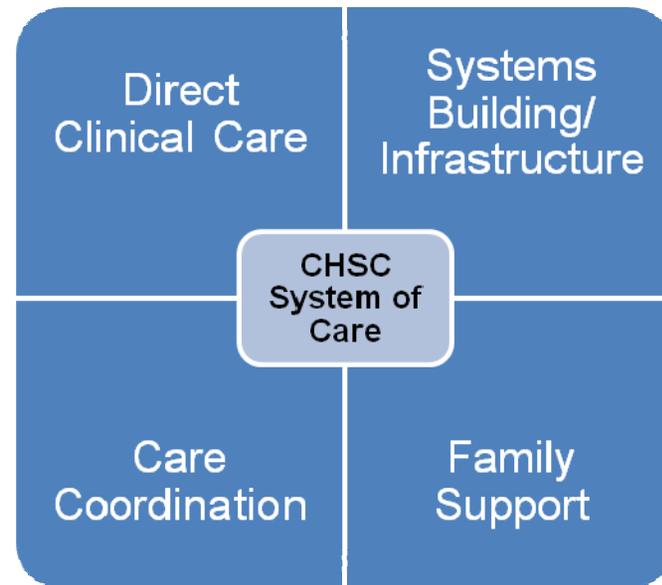
- Getting youth involved in a meaningful way
 - Marketing
- Collecting data – no one likes to collect data!
 - Sustainability?

Next steps -- assuring Family Support after the grants end

- Building Family Support into a *System of Care* for CYSHCN
- Transfer to a nonprofit organization
- Linking with resources funded by long-standing agencies and programs and medical homes
- Exploring reimbursement options



Assuring a **System of Care** for Iowa's Children and Youth with Special Health Care Needs



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