



**R A P**

Iowa Regional Autism Assistance Program

# *Shared Resource: Iowa Child Health Connections*

**Collaborative Peer-to-Peer Exchange**

Wednesday, June 15, 2016

Richmond, VA

Peggy L. Swails, MSW, LMSW, Program Manager

# Collaboration

- o August 2014 - CHSC was awarded a two-year Health Resources and Services Administration (HRSA) state implementation grant, *Improving Services for Iowa's Young Children with Autism Spectrum Disorder and Other Developmental Disabilities* (HRSA-13-207).
- o To maximize the use of this funding, CHSC collaborated with partners from the Iowa Department of Public Health's (IDPH) HRSA systems implementation grant, *Enhancing a System of Care for Iowa's Children and Youth with Special Health Care Needs* (HRSA-14-030).
- o **Goal:** To develop a robust statewide resource for CYSHCN, their families, and providers who care for them.



## Iowa Child Health Connections

- o Iowa Child Health Connections (IHC) site went “live” in March 2016
- o This dynamic website provides comprehensive information for families and providers including diagnosis information, tips on working with schools and educators, and a searchable resource database with over 2,000 resources and services available to Iowa families.

<http://www.iowachildhealthconnections.com/>



## Supporting families and providers

Specialized services and programs help identify health care needs and outline the long term care plan. Our health care specialists are here to assist you, your child and your family.

Iowa Child Health Connections is a resource for children and youth with special health care needs, their families, and the providers that care for them.

[View Information for Parents & Families](#)



*Over 150,000 Iowa children and youth have special health care needs including chronic physical, developmental, behavioral, and emotional concerns.*



Iowa Child Health Connections provides information about community-based services and resources for children and youth with special health care needs and their families.

[View our Resources](#)



# Parents & Families Roadmap

Home > Information for Parents & Families

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The following interactive roadmap provides access to information and resources regarding diagnosis, early childhood, education, family support, assistive technology, finances/benefits, transitions, and legal issues. Please click on one of the options below for more detailed information on each topic.





## Providers Roadmap

[Home](#) > [Information for Providers](#)



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The following interactive roadmap provides access to information and resources regarding children and youth with special health care needs, building a medical home, screening and prevention, diagnosis information, working with schools, medical technology, and transitions. Please click on one of the options below for more detailed information on each topic.



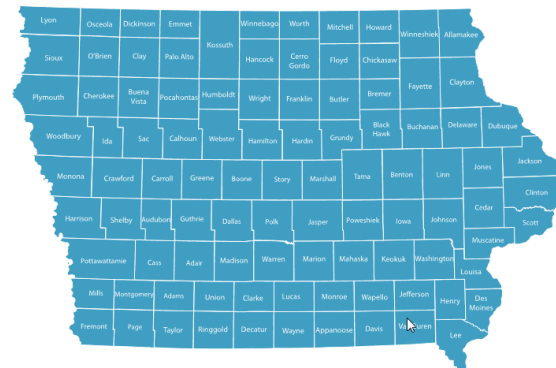


## Resources Search

Home > Resources Search

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Use the below search or click on a county to find community-based services and web-based resources.





## Self Care and Family Care

Home > Information for Parents & Families > Self Care and Family Care

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### More Information

**Family Voices:**  
Family-led organization promoting quality health care for children and youth with special health care needs

**ASK Resource Center:**  
Parent training, information, and advocacy center for Iowa families of children with special health care needs

**Family to Family Iowa:**  
Statewide network of Family Navigators who provide assistance to families of children with special health care needs

**Sibling Support Project:**  
Supports siblings of children with special health care needs. Started "Sibshops" to provide peer support and information to siblings in a recreational setting.

### Information for Parents & Families

Diagnosis Information for Families

Services for Children 0-5 Years Old

Education and Schools

Support for Transition

Financing Children's Health Care

Assistive Technology

Self Care and Family Care

Legal Issues

Research shows that parents of children and youth with special health care needs experience higher levels of stress, anxiety, and depression. Seeking support for themselves can help parents maximize their own strengths, capability, and capacity to care for their child.

### Self-Care

Most people think it's strange when an airline attendant instructs you to put on your own oxygen mask before helping other in an emergency. But believe it or not, the airlines might be right. In order to take care of others, parents and caregivers must first take care of themselves.

Different types of emotional and informational support may include: support groups, therapy or counseling, developing advocacy skills, peer mentoring, or respite care.

- In what areas do you need help? Make lists of ways people can help you, so when they offer, you can be ready with some ideas. Even small acts like cooking a meal or staying with your child for a couple of hours can make a difference.
- What resources are there to help you? Don't forget community, friends, family, and religious affiliations.
- Put together a [Care Notebook](#). Organize and write down your child's health care information and schedule including medications and activities.
- Explore respite care options. Respite care is temporary care for children with special health care needs. Temporary can mean for a few hours or a few days, periodically or on a regular basis.

### Family Care

Siblings of children and youth with special health care needs often have their own challenges. Children are just as affected by their sibling's diagnosis as the rest of the family, and it may be difficult for them to sort through their feelings and concerns.

- Devote quality time to other children and if possible, schedule some alone time on a regular basis.
- Consider the feelings other children may have toward their sibling with special health care needs. These feelings may include guilt, embarrassment, resentment, or grief.
- Use appropriate and straightforward language when communicating and answering questions about a sibling with special health care needs.
- Find ways to let your other children be involved in caring for their sibling with special health care needs, but make sure you do not ask too much of them. Maintain balanced, healthy expectations regarding siblings serving as caregivers.





# Future Developments

- o Further enhancements are in development, including a YouTube™ channel to broadcast recorded trainings for families, self-advocates, and providers.
- o YouTube™ channel will also allow families to share their experiences (e.g. the use of Family Navigators).
- o Team members from both projects, including family advisors, will continue to meet regularly to develop, review, and update the content for this ICHC site.

# Sustainability

- o Use of Blended funds :
  - o Title V
  - o State of Iowa (Iowa Department of Education, Iowa Department of Public Health)
  - o Potential funds from federal grants and other state contracts

# Social Media



Iowa Regional  
Autism Assistance  
Program



Iowa Regional  
Autism  
Assistance  
Program



Iowa RAP

# RAP on YouTube™

Iowa Regional Autism Assistance Program

0 subscribers Video Manager

**Welcome!**

**RAP**

**Iowa Regional Autism Assistance Program** Settings Subscribe 0

The mission of the Iowa Regional Autism Assistance Program (RAP) is to assure community-based clinical consultation, multidisciplinary care planning recommendations, and family-to-family support for children with Autism Spectrum Disorder (ASD) and their families. [Show less](#)

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# Thank you!

Peggy L. Swails, MSW, LMSW

[peggy-swails@uiowa.edu](mailto:peggy-swails@uiowa.edu)