The Iowa Regional Autism Assistance Program: Engaging Effective Partnerships to Enhance Systems of Care While Building Sustainable Programs

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Objectives

- Increase Awareness of the Division of Child and Community Health, Child Health Specialty Clinics’ (CHSC) role in building a system of care for Iowa’s children and youth in Iowa with special health care needs (CYSHCN)
- Provide Overview of the Iowa Regional Autism Assistance Program (RAP)
- Describe RAP team members and their roles, including the RAP Family Navigators
- Discuss lessons learned and strategies used to assure sustainability of program elements
The University of Iowa Carver College of Medicine
Stead Family Department of Pediatrics
Division of Child and Community Health
Iowa’s Title V Program for CYSHCN
Child Health Specialty Clinics

Our Pillars of Strength

Leadership in Statewide Systems of Care for CYSHCN
Providing Iowa’s Title V Services for CYSHCN in Regional Centers
Creating Integrated Partnerships and Community-Based Models of Care

Established Statewide Partnerships

- Iowa Departments of Education, Public Health, and Human Services
- Managed Care Organizations
- American Academy of Pediatrics – Iowa Chapter
- Iowa’s 1st Five Healthy Mental Development Initiative (Help Me Grow)
- Iowa’s federally designated Family-to-Family Health Information Center (HIC) and also federally designated Parent Training and Information Center (PTIC)
- University of Iowa Colleges & Children’s Hospitals
- Iowa’s University Center for Excellence on Developmental Disabilities (UCEDD)
- Iowa’s Leadership Education in Neurodevelopmental and Related Disabilities (LEND) Program
The mission of the Iowa Regional Autism Assistance Program 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.
Child Health Specialty Clinics (CHSC) combines resources to administer RAP

This includes resources from:
- Iowa Department of Education
- Iowa Department of Public Health
- Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS)*

*Project period 9/1/2014 – 3/31/2017

History of RAP
Legislation in 1990 created the Regional Autism Assistance Program.

Iowa Code 256.35 Regional Autism Assistance Program
The Department of Education shall establish a regional autism assistance program, to be administered by the Child Health Specialty Clinics of the University of Iowa Hospitals and Clinics. The program shall be designed to coordinate educational, medical, and other human services for persons with autism, their parents, and providers of services to persons with autism.

Function of RAP

256.35 Regional Autism Assistance Program (continued)
The function of the program shall include, but is not limited to, the coordination of diagnostic and assessment services, the maintaining of a research base, coordination of in-service training, providing technical assistance, and providing consultation.
RAP’s Commitment

RAP teams are committed to ensuring that Iowans ages 0-21 years with ASD and their families have access to early identification, treatment services, care coordination, and family-to-family support in their community.

RAP Team Members

- Advanced Registered Nurse Practitioners
- Registered Nurses
- Family Navigators

Roles of RAP Team Members

RAP teams provide care coordination and family-to-family support by:

- Communicating with diagnostic facilities and health care providers
- Exploring insurance coverage and payment options for Applied Behavior Analysis and other intervention services
- Navigating education and other systems with a Family Navigator
- Finding an advocacy or family support group
- Connecting families to ASD resources
Figure 1: Number of Families Served by the Iowa Regional Autism Assistance Program, 2014-2016*

<table>
<thead>
<tr>
<th>Year</th>
<th>Number Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>FY2014</td>
<td>86</td>
</tr>
<tr>
<td>FY2015</td>
<td>259</td>
</tr>
<tr>
<td>FY2016</td>
<td>577</td>
</tr>
<tr>
<td>FY2017</td>
<td>862</td>
</tr>
</tbody>
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* These numbers represent families being served by RAP - both new and ongoing

Highlighted Project Activities

- Created Family Navigator Coordinator position
  - Received delegate for an Act Early Ambassador for the state of Iowa
- Developed a robust statewide resource for CYSHCN, in collaboration with HRSA-funded State Integration Grantee (HRSA-14-030), Iowa Child Health Connections (ICHC).
- Created RAP Family Advisory Council
- Developed Statewide Strategic Plan
- Conducted surveys of families enrolled with RAP, Pediatric Dentists, and Diagnostic Providers to assess knowledge of statewide referral and ASD resources
- Distributed free resources available from the CDC’s Learn the Signs. Act Early. (LTSAE) program
  - Provided several trainings and Grand Rounds presentations to medical students, LEND trainees, Head Start/Early Head Start, AEA’s, Early ACCESS, ASK, and CHSC regional center teams on LTSAE, developmental & ASD evidence-based screening tools
  - Developed guide, Navigating Iowa’s System of Care: A Caregiver’s Guide to Autism Spectrum Disorder – Next Steps After Diagnosis
  - Held Symposium in July 2016, Autism and Your Family: A Spectrum of Support During Early Childhood
  - Developed a brochure for families describing the concept of the Medical Home
  - Increased access to Family Navigators by developing process for a Family Navigator Consult in electronic medical record
Strategies for Sustaining Project Initiatives

Family Navigator Coordinator Position
- Uniquely positioned to support Family Navigator Network with RAP
- Creative budget strategies to sustain position
- Act Early Ambassador for CDC’s Learn the Signs. Act Early. campaign

Website: Iowa Child Health Connections

http://www.iowachildhealthconnections.com/
Statewide Strategic Plan

- Adopted by the Iowa Autism Council
- Identified Champions for each area of focus to assure Implementation
- Utilize Collective Impact Theory
- Provide updates at Quarterly Council meetings


Partner with Early Childhood Providers to Increase Awareness of LTSAE

Dedicate space on website for Iowa Act Early Information
Maintain Social Media Campaign Efforts

Iowa Regional Autism Assistance Program
Iowa RAP

Disseminating Caregiver Guide to Newly Diagnosed Families

Title V CYSHCN: National Performance Measure - Medical