

IOWA FAMILY LEADERSHIP TRAINING INSTITUTE

UNIVERSITY OF IOWA DIVISION OF CHILD AND COMMUNITY HEALTH
CHILD HEALTH SPECIALTY CLINICS

Introduction

The Iowa Family Leadership Training Institute was developed to provide parents and caregivers of Children and Youth with Special Health Care Needs the opportunity to develop leadership and advocacy skills. Developed by the University of Iowa Division of Child and Community Health and Child Health Specialty Clinics, this program builds on the existing infrastructure of Iowa's Maternal and Child Health Title V Block Grant Program for Children and Youth with Special Health Care Needs.

Family Support in Iowa

Iowa's First Family Navigator

Child Health Specialty Clinics (CHSC) has been providing direct support to families for over 35 years, hiring Iowa's first Family Navigator, Julie Beckett, in 1984. Julie was the mother of Katie. When Katie was 5 months old, she contracted encephalitis, was left partially paralyzed, and spent most of her early years in the hospital. When she was 3 years old, doctors cleared Katie to go home, although she still needed to be on a respirator for 12 hours a day. Her insurance had been depleted and Medicaid refused to pay for her care unless she was hospitalized, even though treatment could be administered to Katie at home for one-sixth of the cost.

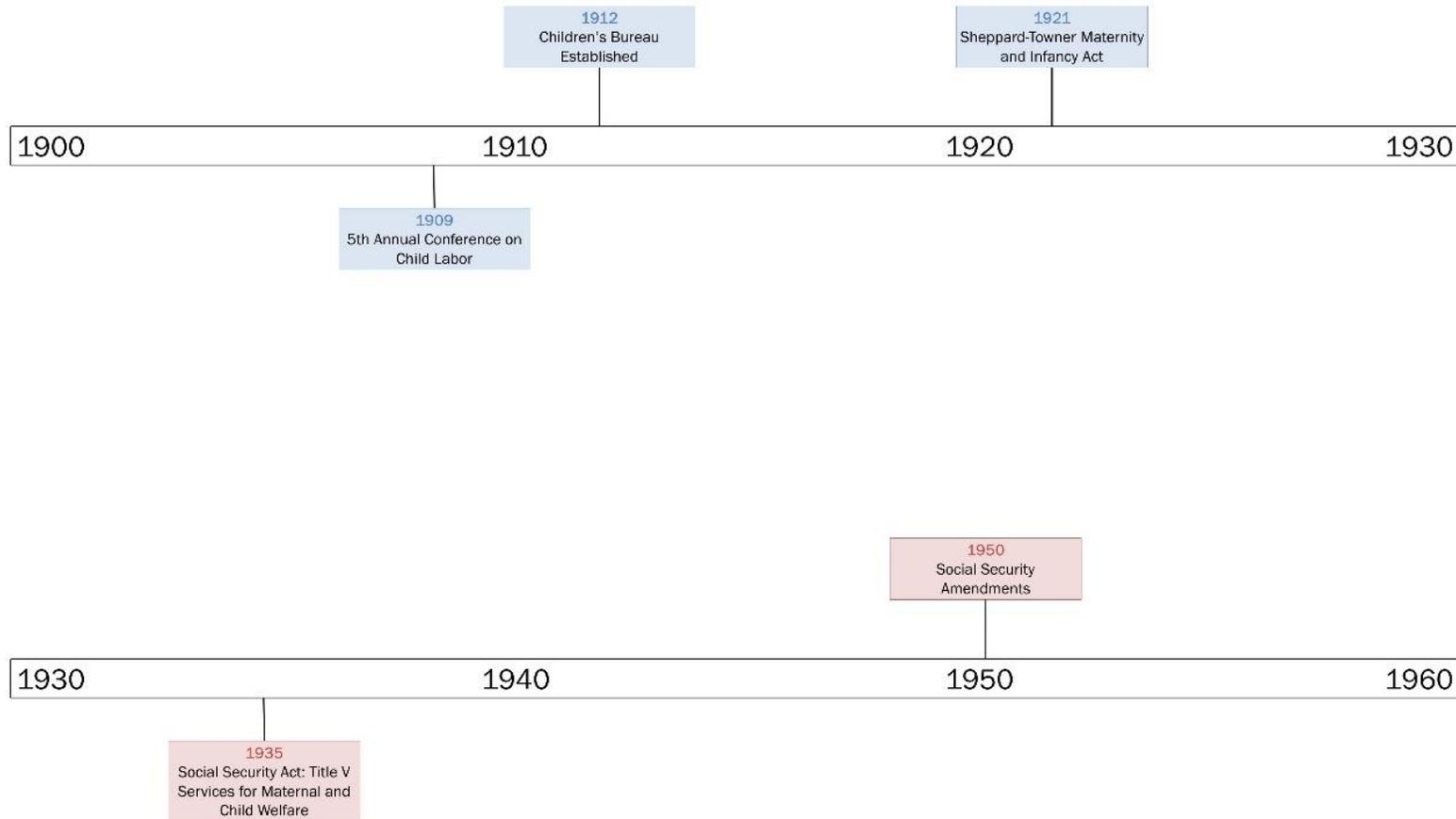
Julie Beckett advocated for her daughter to be able to receive care at home, and in 1981, Katie's case got the attention of President Ronald Reagan. President Reagan not only waived the rule so that Katie could go home, but in 1982 signed what became known as the "Katie Beckett Waiver" allowing all children with disabilities to receive Medicaid supports at home.

Although Katie died in 2012 at the age of 34, the legislation that bears her name (also known as the Health and Disability Waiver) has allowed hundreds of thousands of children receiving Medicaid to remain at home with their families instead of being institutionalized. Julie worked at CHSC for 30 years and now serves as a consultant with Family Voices and the American Academy of Pediatrics.

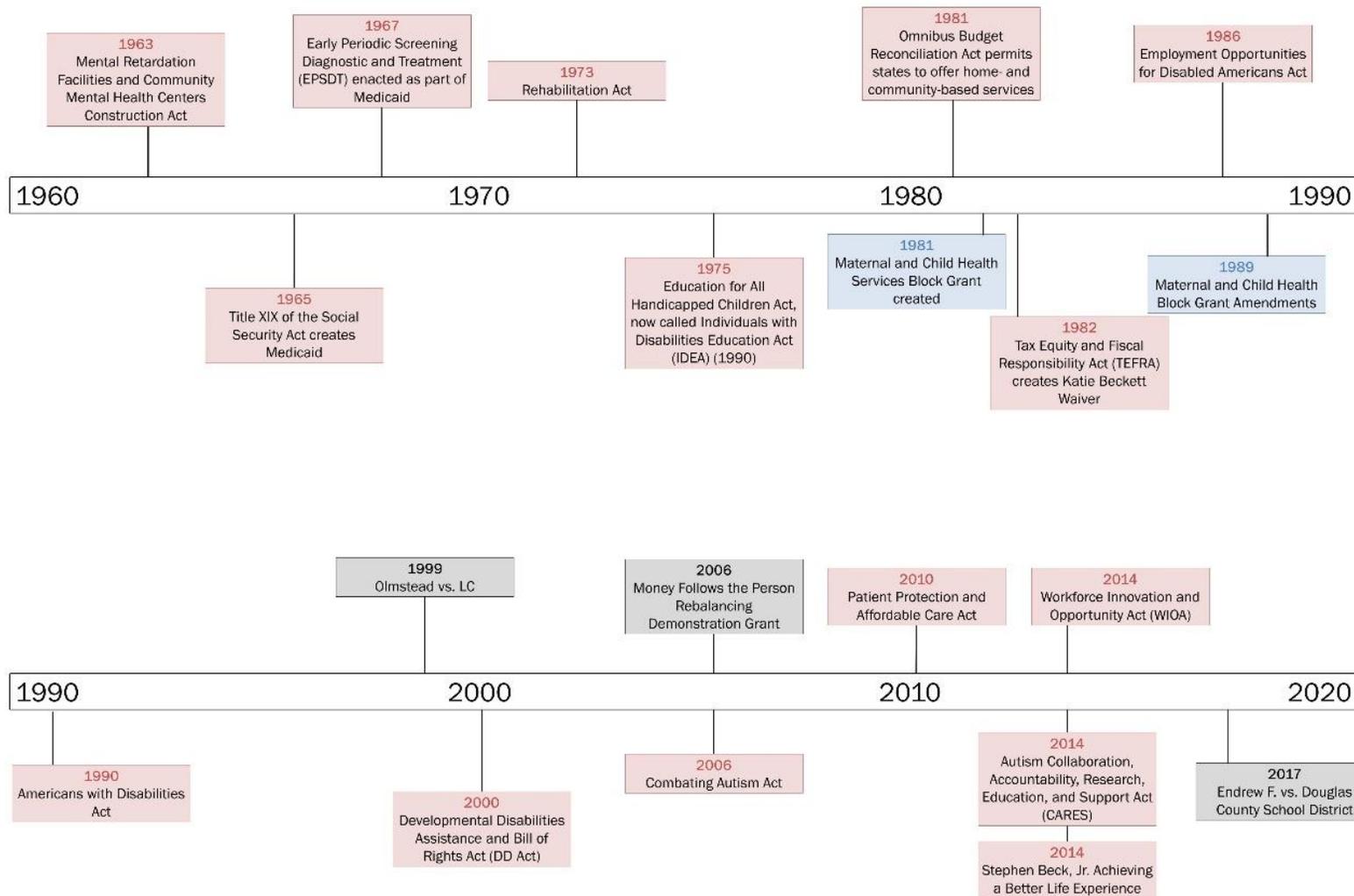


Julie and Katie Beckett leaving the hospital

History of Disability Legislation and Legal Decisions in the United States 1900-1960



History of Disability Legislation and Legal Decisions in the United States 1960-2020



CHSC Family Navigator Network

CHSC currently employs over 30 Family Navigators, all of whom are the parent or primary caregiver of a child or youth with special health care needs. Family Navigators are based at all 14 Regional Centers across Iowa, living and working in the communities they serve. In addition to providing support to families, these professionals also provide meaningful input from the family perspective to all CHSC programs, policies, and initiatives.

2016 Session

In 2015, momentum was building among family leaders across the country to train families of Children and Youth with Special Health Care Needs in leadership and advocacy skills. While parents and caregivers have significant life experience in the world of special needs, they may not have the training to partner with professionals at all levels. Family leadership training increases the capacity of caregivers to communicate better with providers, work with community partners, and make health care systems more family-centered. In March 2016, a group of CHSC Family Navigators launched the inaugural session of this training.

- Nine months long
- Mostly virtual one-hour trainings with one in-person session
- Maternal and Child Health Leadership Competencies served as the framework
- Mentoring conducted in small groups
- Sessions were presentations by national and state leaders
- 35 parents and grandparents of CSHCN applied, 25 were accepted
- Participants were from all areas of Iowa
- Individual Leadership Projects were required

A post-training evaluation revealed the need for improvement in these areas:

- Clarification of desired outcomes
- Definition of target audience
- Training format
- Role of mentors
- Community Service Project

Technical Assistance

CHSC staff applied for and received technical assistance funding from the Health Resources and Services Administration to work with Librada Estrada Consulting, an organization specializing in professional coaching and facilitation. Over a period of six months, CHSC staff worked with Ms. Estrada to review and revise the training curriculum based on several lessons learned.

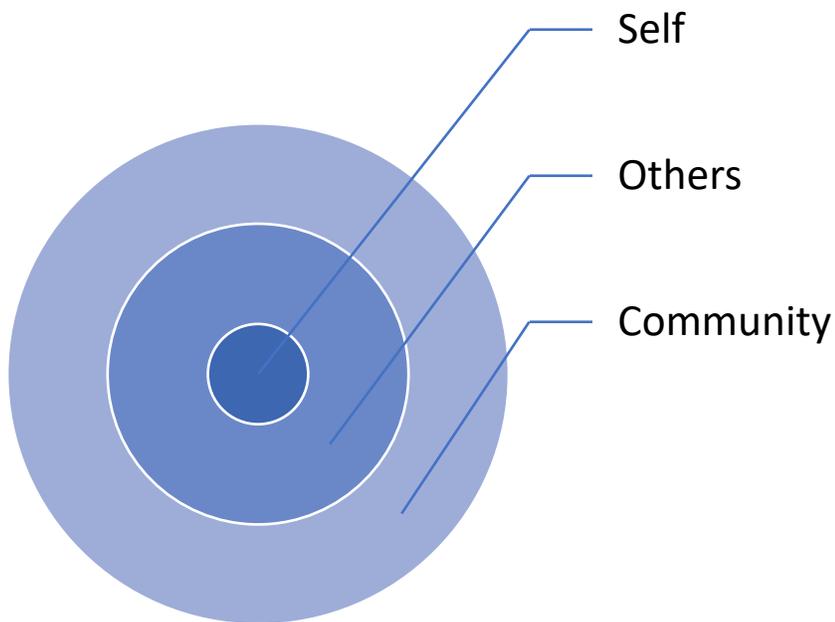
Clarification of desired outcomes

In collaboration with Ms. Estrada, new objectives were developed for the training program:

1. Understand how to work with partners
2. Become aware of one's own path to leadership
3. Discover strategies for advocacy
4. Prepare a Community Service Project having impact at the community or systems level

The mission was defined as the preparation of emerging family leaders to engage in advocacy at all levels (individual, community and systems) to improve policies and services for Iowa children with special health care needs and their families.

The Maternal and Child Health Leadership Competencies were used as a framework for developing these the new objectives. Figure 1 illustrates with widening spheres of influence that leaders experience as they develop from self to others to the wider community¹.



The leadership process begins with the focus on self where leadership is directed at one's own learning. Leadership in the next sphere extends to others as they are influenced and possibly altered through interactions with the individual. Leadership can also extend to a broader impact through additional skills and a broader based understanding of the change process.

¹ MCH Leadership Competencies. <https://mchb.hrsa.gov/training/leadership-00.asp>

Definition of target audience

CHSC staff worked with Ms. Estrada to identify the “ideal participant” for the training, understanding that not all applicants should be accepted into the program. Staff looked for individuals who had some involvement with previous training or with a disability-specific organization, had a desire to develop their leadership skills and grow through mentorship, and were relatively settled in their family life. Applicants were asked to provide two references, complete a screening questionnaire and participate in an interview with staff. Training staff rated each candidate using a scale from one to five, recognizing that defining readiness led to a stronger cohort. The ideal cohort size, 12-15 trainees, was established.

Training Format

After consultation with the Massachusetts CYSHCN program, the training format was changed from virtual to in-person, including an overnight stay. This resulted in more contact hours and opportunities for trainees to interact and socialize with one another outside of the structured training sessions. To reduce the need to travel long distances, participation was limited to individuals from a specific region of the state and the format was changed to four sessions over four months.

Staff also decided to engage local experts rather than national speakers for the 2017 session. CHSC Family Navigators were recruited to develop and deliver trainings along with partners from the University of Iowa and community organizations. The Maternal and Child Health Leadership Competencies framework was retained with emphasis on interactive sessions.

Role of Mentors

During the 2016 session, there were only five mentors for 25 participants. In the revised training, the number of participants was reduced in order to provide one-to-one mentoring. Guidelines were developed to further define the role of mentors, who were selected based on their experience as parents of CYSHCN and as advocates at the state or national level. Mentors were asked to help participants with the development of their Community Service Project and were required to be in regular contact between training sessions.

Community Service Project

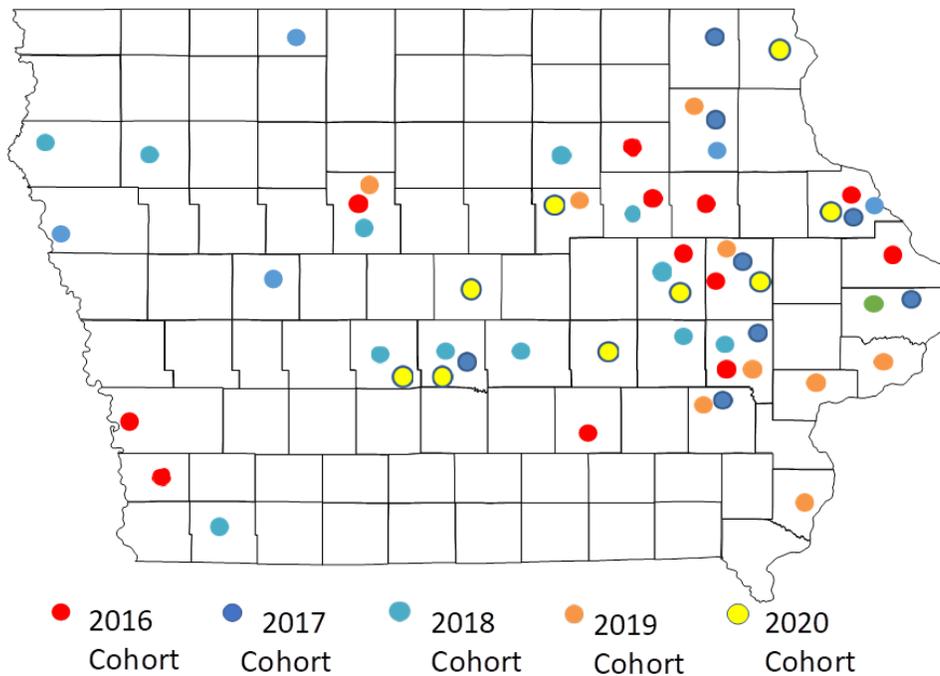
The name of the final project was changed from Individual Leadership Project to Community Service Project. During the 2016 session, several trainees had goals that were unattainable or overly ambitious and some projects didn't meet the community impact criteria. The guidelines for this project were revised to help trainees identify realistic goals. A series of worksheets were developed to help participants identify specific timelines, interact with their peers, and provide feedback to the trainers. Participants were encouraged to think about the impact of their project at the community or systems level and to engage other community partners. A protocol was developed for trainees who were either not meeting the expectations of the Community Service Project and/or the required contact hours with their mentor.

2017-2019 Sessions

Over the next three years, 39 additional participants completed the Training Institute. Trainees were selected based on:

- Cross-diagnosis representation
- Urban/rural distribution
- Ethnic, economic and cultural diversity
- Previous training or community engagement
- Readiness to participate.

Locations of Training Participants 2016-2020



All participants were the parent or primary caregivers of a child or youth between the ages of 2 and 19 years old. Most participants were women; however, two men have participated, and an additional father served as a mentor. An Arabic interpreter joined the 2017 training, and the written materials were translated into Arabic. Stipends were provided for those who identified financial stressors.

Recruiting required focused effort. Parents are busy, often do not detect leadership qualities in themselves, may struggle with committing to a four-month-long training, and may not have enough support to attend an overnight training. Often parents need a personal invitation to enroll and encouragement to sustain involvement. Invariably they are motivated by the shared

experience of training. All the cohorts have developed private Facebook pages to continue communication. The Institute also maintains a Facebook page.

Evening Training Sessions

Project staff received feedback from some potential participants that they were unable to attend the full training due to unpredictable work schedules or unreliable transportation. With funding from the National Network of Libraries of Medicine, Greater Midwest Region, modules from the training were delivered in two-hour-long, evening trainings in communities around the state. Local Family Navigators recruited participants for these trainings and co-presented with an Institute trainer. Topics included finding reliable health resources, communication, advocacy, and family-centered care.

Ongoing Engagement

In order to continue engagement with former participants, continuing education opportunities were offered through evening webinars. Topics included Adverse Childhood Experiences and legislative advocacy. Presenters were state and local leaders and previous mentors. In 2019, a former participant volunteered to produce a newsletter for graduates of all cohorts.

Evaluation

An evaluation of this project was launched during the summer of 2019. Graduates of all four cohorts were invited to be interviewed and asked to reflect on their own growth in leadership and current involvement in their communities. Conclusions from these interviews were:

- The IFLTI trained participants to recognize and develop their own leadership skills and expertise as parents of CYSHCN
- Participants gained the confidence and skills to develop community and system-level partnership
- IFLTI encouraged continuing connectedness among cohorts
- While family training positively impacts the system of care for CYSHCN, more research is needed to measure impact over time

2020 training

The 2020 session of IFLT launched in March with 10 trainees. Within two weeks, COVID-19 bore down on the state, and in-person trainings and meetings were cancelled. IFLTI staff, in consultation with trainees, converted to virtual trainings for Sessions 2, 3 and 4. Four trainees withdrew from the training due to increased family responsibilities or health concerns. Those who remained reported barriers to making progress on Community Service Projects. In time, trainees modified their projects or adjusted goals to reflect restrictions imposed by the pandemic. Focus of the training shifted to identifying personal leadership growth and maintaining wellness. Plans are to reconvene in person in fall 2020 if public health guidelines allow.

Associated Trainings

In spring 2019, project staff partnered with Mothers on the Frontline, an Iowa nonprofit serving mothers of children with serious mental illness, to host a digital storytelling workshop presented by StoryCenter of Berkeley, CA. Funding was secured from the Iowa Developmental Disabilities Council to host a digital storytelling training in June 2020. The training was postponed to 2021 due to COVID-19 restrictions.

In fall 2019, Iowa Department of Education requested a partnership with IFLTI staff to revise a longstanding parent storytelling training, Parents as Presenters. Renamed Storytelling for Family Leaders, the virtual training is expected to launch in 2020.

A new webinar series to prepare families to partner with schools and medical providers at the individual level launched in June 2020. This eight-part training, called Navigating Special Needs, will be delivered virtually through October 2020.

Impact

It is difficult to quantify the impact of IFLTI on individual trainees' lives. One trainee said, "I learned I was a leader and could do great things." Another said, "I learned so much and feel competent as a family leader and servant leader. I am so lucky to have found 'my people.' I truly feel I have found my calling in life, that is, to continue to make positive changes in the lives of families and youth with special health care needs."

The 2019 evaluation project showed graduates' growth in leadership, advocacy and partnering skills. Partnerships developed through Community Service Projects have resulted in family-professional partnerships across the System of Care for children with special health care needs including state legislation, community support groups and events, invitations to serve on state boards, employment as family peer support specialists and trainings for school staff.

Relationships built with state family-serving organizations and with seasoned family leaders serving as mentors has created an infrastructure to advance shared training and development of family leaders as well as family-friendly policies and advocacy. Work to build a family leader registry and to refine desired outcomes of IFLTI continues.

In early 2020, project staff were asked to present a poster at the 2020 Annual Conference for the Association of Maternal and Child Health Programs. This conference will be held virtually August 4-6, 2020.

Community Service Projects 2016-2019

Shenandoah, IA

Formed an Autism Task Force in southwest Iowa. This group held a sensory-friendly holiday party and a sensory-friendly screening of *Mary Poppins Returns*.

Shell Rock, IA

Researched caregiver resilience and advocated with several providers to implement a caregiver resilience screening tool.

Callender, IA

Worked with state legislators to introduce a bill requiring adult changing tables in public space.

Oelwein, IA

Hosted family event to draw attention to need for sibling support

Iowa City, IA

Designed an All About Me to tell teachers about a child's diagnosis, what works for the child as well as triggers

Cedar Rapids, IA

Developed a sustainable method to share transition services information to parents through social media and a convenient email newsletter

Iowa City, IA

Filmed a seminar titled "LGBTQIA+ What Do the Letters Mean?" and completed an extensive list of resources for viewers

Sheldon, IA

Support group for parents of children with special health care needs to find resources, educate others, and make the community better for their children and youth

Dubuque, IA

Collaborated with Iowa Vocational Rehabilitation to produce a video for family members and guardians about integrated employment

Estherville, IA

Formed the Parent-Led Empowerment and Advocacy for Disabilities (PLEAD) group.

Glidden, IA

Formed Cerebral Palsy Parents of Iowa Facebook group; seeking merger with national organization.

Hawarden, IA

Education of First Responders on needs of persons with disabilities, partnering with Emergency Management Services on outreach

Eldridge, IA

Arranged for a deaf adult to teach ASL to 1st- and 2nd graders. Has joined board of Iowa Hands and Voices

Glenwood, IA

Created a one-page profile for my son who is transitioning to middle school

Vinton, IA

Participated as a parent representative in a Family Educator Partner (FEP) group, helping to redesign the role of the FEP in the state

Maquoketa, IA

Spread more awareness about epilepsy in the community

Independence, IA

Created a Families as Faculty project for medical students modeled on one in New Mexico

Riverside, IA

Developed a plan to work with lawmakers to amend Iowa law to protect children with special needs from bullying in schools

Des Moines, IA

Developed a website to house autism resources for families in central Iowa

Clinton, IA

Created a resource folder for teachers in my school district with information about “invisible” disabilities: Dyslexia, Dysgraphia, Dyscalculia, Dyspraxia, and Nonverbal Learning Disability

Cedar Rapids

Made a plan to tell policymakers about how the shortage of home health nurses affects families of children with special needs

DeWitt, IA

Made a plan to work with my state legislator to introduce legislation requiring insurance to pay for pediatric hearing aids

Des Moines, IA

Worked with my children’s school to start an on-site support and resource group for parents of children with special needs

Hudson, IA

Partnered with neighbors to start the only AMBUCSs chapter in Iowa

Dubuque, IA

Introduced the Gallup StrengthsFinder assessment to the paraprofessional team at my children’s school

Decorah, IA

Created a simple Top 10 List of resources and things to do to help special needs children thrive and access critical services and supports, relieving parents’ unnecessary stress after a diagnosis

Cedar Rapids, IA

Founded Iowa Hydrocephalus Association Community Network to meet the needs of parents of children with Hydrocephalus for support, education and advocacy

Dubuque, IA

Created an Autism Connections Group in my county to provide information and support to families of a child with autism and help them locate community resources

Iowa City, IA

Created a model for a parent panel to provide education about the types of waivers and how waivers have impacted their lives

Iowa City, IA

Developed a plan for supporting families of children with mental health needs and learning disabilities in my community

Oelwein, IA

Partnered with Iowa’s Early ACCESS program to create a digital story about my experience of delayed early intervention services

Des Moines, IA

Created a social media group for gender nonconforming children on the autism spectrum

Carroll, IA

Organized speakers and researched funding for a support group in the community

Grimes, IA

Developed a "Places to Play" list, recreational areas accessible to children with special needs and their families

Amana, IA

Partnered with a national organization to offer peer support to parents facing a prenatal diagnosis and choosing to carry to term

Mount Vernon, IA

Provided guidance to school districts on how to consider a student's IEP when administering a good conduct violation in extracurricular activities

Des Moines, IA

Researched how make the Home- and Community-Based Services waiver application process more understandable for families of CSHCN

Ainsworth, IA

Created a parent support group in my community, starting with an ice cream social and a family water balloon fight

Tiffin, IA

Partnered with social workers in my school district to create a resource list for parents of children with special needs

West Liberty, IA

Worked with my AEA to schedule a special education training for Spanish-speaking families of children with special needs

Dike, IA

Met with school administrators to discuss the need for training for teachers on Autism Spectrum Disorder

Oelwein, IA

Created an online website to promote caregiver-to-caregiver communication and a foundation to fund self-care strategies

Cedar Rapids, IA

Created a Facebook page to educate people about improving the quality of life through health

West Burlington, IA

Developed a plan to connect families of children with special needs in my area

Fort Dodge, IA

With my school district, developed para educator resources for supporting Autism Spectrum Disorders

Sloane, IA

Created a resource guide for parents of children discharged from the Neonatal Intensive Care Unit