



Stead Family
Pediatrics

Iowa Family Leadership Training Institute

Community Service Project Look Book

A look into Iowa Family Leadership Training Institute (IFLTI) alumni projects- This is an overview of projects worked on by family leaders during their IFLTI training.

Summaries may not fully represent ongoing projects or the finished product due to changes during project development or unforeseen barriers. This Look Book focuses on the projects completed during the course of this training. These projects were developed to address service gaps that participants identified in their communities.



www.chsciowa.org/iflti

INTRODUCTION

The Community Service Project (CSP) is a vehicle for IFLTI participants to practice leadership skills: both skills introduced during in-person sessions and leadership goals the participants set for themselves. The CSP is designed to address a gap participants see in the system of care for children and youth with special healthcare needs, a gap that affects more than just one's own family. Requirements are that the project has an impact at the community or state level, involves some collaboration with partners in the community or state, is a new project developed for this training and doesn't duplicate other projects in the state. Participants receive one-on-one mentorship for the Community Service Project.

The Iowa Family Leadership Training Institute (IFLTI) provides parents and caregivers of Children and Youth with Special Health Care Needs (CYSHCN) the opportunity to develop leadership and advocacy skills. Created in 2016 by University of Iowa Division of Child and Community Health and Child Health Specialty Clinics (CHSC), this program builds on the existing infrastructure of Iowa's Maternal and Child Health Title V Block Grant Program for CYSHCN. The training teaches participants to lead advocacy activities and to work with partners and stakeholders to implement a community service project.

IFLTI is grateful for various partners and co-sponsors over the years: National Library of Medicine, Iowa Developmental Disabilities Council, University Center for Excellence in Developmental Disabilities, The ARC and Molina Healthcare

2025

Iowa City

Celiac Training in Schools: Providing scripted, interactive, in-person training for schools, shared online at www.beyondceliac.org and to be shared directly.

Marion

Wings for Autism: Collaboration with the Cedar Rapids Regional Airport to provide events for children with autism to be familiarized with airports and the processes.

Cedar Falls

Proposing an ADA subcommittee to the Cedar Falls city council: Presented to the city council to raise awareness of issues families with disabilities are challenged with and discussed what steps could be taken to ensure compliance with ADA.

Spirit Lake

Universal Changing Tables for the Iowa Great Lakes Advocacy for universal changing tables at Arnold's Park and Great Lakes region.

Glenwood

Accessible Playground: Partner with the school PTA and administration to include more accessible playground equipment into the new playground build that is taking place.

Coralville

Sensory Training for Elementary Paraeducators: In partnership with a local occupational therapist, training will be offered to the teaching staff at the Montessori Children's Garden as a pilot training.

Ames

Support & Advocacy Group: Planning a support and advocacy group for parents and caregivers of children and youth with special health care needs in the Ames area.

Akron

In the Quiet: A retreat for parents and caregivers of children and youth with special health care needs to connect, receive tools to return home with and to rest.

Lisbon

Adaptive 4-H: Create a new opportunity for special needs families to engage in a 4-H program in our community with adaptive participation.

2025

North Liberty

Caregiver Mental Health Awareness Event: Virtual event focusing on caregiver mental health, providing a personal story, self-care survey and tips and resources presented by ASK Resource Center.

Johnston

Smiley Support & Plays: In-person support and play groups through the summer for all families and an online page, including blogs and resources for families.

Marion

Bibs for Big Kids: Making and gifting bibs to families of children with special health care needs.

2024

Huxley

EmbracAbility for Churches: Training video and resource packet to help churches become more inclusive for those with disabilities to be able to fully participate.

Indianola

Vision for the Future: A resource guide for parents of children with Peter's Anomaly.

Coralville

Solo-Parenting while Navigating Autism-Support Group: Support group for solo/single parents within the community. This group will meet in person every three months and will provide resources to families.

Reinbeck

Seatbelts Can Communicate Too: Advocacy for seatbelt covers that display information about a child, such as their name and their diagnosis.

Panora

Guthrie County Support and Play: A monthly play group designed for children and youth with special health care needs and their families. This group will organize monthly play activities while providing support and resources to parents.

Indianola

Indianola Support Network for Special Needs Families: An online community for families and caregivers in the Indianola area who have children with special needs. This group was created to foster connections and relationships between families/caregivers, so no one feels they are alone on their journey.

Iowa City

Defensor de necesidades especiales: Abogó por que los conductores de autobuses escolares reciban capacitación adicional para trabajar con niños con necesidades especiales.

Special Needs Advocate: Advocated for school bus drivers to be provided with extra training for working with children with special needs.

Carroll

Social Emotional Learning for Childcare Providers: I am working to provide training to childcare providers for individuals with social/emotional and regulation issues.

Algona

Project Inclusion: I am working with Algona schools to add communication boards to the school playgrounds and fencing around the elementary school playground for children who elope.

Arcadia

All-Star Allies - Heroes, Together in Sports: I partnered with the schools and a local little league organization to pilot a buddy program for children and youth with special health care needs who need extra assistance to be able to participate in extracurricular activities.

Liscomb

Be the Change, Weighted Blanket Project: I organized a group of volunteers to make six weighted blankets to be donated to our local special education elementary classroom. I also used this opportunity as a lunch and learn to spread education and awareness about Autism.

Fort Dodge

Pioneering for Special Youth: I gathered information through interviews and research to create flyers to educate youth about careers in occupational therapy, speech and language therapy and ABA Therapy. This is an effort to recruit/inspire individuals to consider an occupation within the special needs community and increase awareness of these gaps and potential careers.

Ames

Killian & Ko: I founded a non-profit organization whose mission is to provide augmentative alternative communication (AAC) to children ages 2-18 years old diagnosed with autism, apraxia, and other speech disorders.

2023

Mason City

Activities for All: I partnered with local organizations to plan an event for children and youth with special needs in our community.

Huxley

My Great Life: I created educational material to promote soft skills for future employment opportunities.

Marion

Peer Connections: I am working to provide functional skills training as an alternative in school. I am working with partners to provide a program called "I Can Do It", peer mentoring in physical education, sports skills and nutrition.

Dubuque

Marshallese Advocacy Training: I created and delivered advocacy training to the Marshallese parents of CYSHCN to empower families to advocate for their children in the United States.

Decorah

Social Skills Training: I am receiving training in PEERS, an evidence-based social skills training for teens with high functioning autism spectrum disorder, to pilot in the Decorah area.

Coralville

Guide for parents: I am creating a podcast, Iowa Special Needs Parents Crash Course 101, as a guide to parents on how to handle receiving the diagnosis, school, benefits, and other things to think of.

Kiron

Autism in an Emergency: I put together a presentation for local emergency personnel to educate about autism and am sponsoring a Project Lifesaver elopement program for Crawford County.

Johnston

Finding a Faith Home: I've developed a set of reflective questions for parents to think through as they approach a faith organization about their needs.

Marion

Experiences with School Administration when CYSHCN have frequent absences from school: I'm collecting stories from parents about their experiences when their children miss a lot of school because of special health care needs. I'm seeking to help educators understand rather than charge with compulsory violations.

Davenport

Strategic Teaching Tips: I am creating short videos with tips for college educators to assist ADHD students and other neurodiverse populations in the college classroom and submitting them to Magna Publications for online training across the country.

Batavia

Collaborating for Quality: Trainings for paraeducators and associates. I am partnering with local school districts to raise awareness and require training for school paras and associates who work with children with special health care needs without proper training.

Audubon

Supporting Kinship Families: I created a Facebook group to support kinship families who take on fostering their family members to provide support to reduce caregiver burnout, resources, and an understanding of generational trauma. I worked with the statewide Kinship Navigator Program.

Grimes

Build a Better ADA Restroom: I have created an impact video and handout with bathroom design and vendor contact information to improve access for individuals with disabilities by adding height adjustable adult sized changing tables to ADA family restrooms.

Iowa City

Iowa Latin Connections: I have invited all Latin families with a child who has a diagnosis to participate in a support/resource group, El Jabez. They can receive support for their feelings, and resources in the community they need to care for their children.

Iowa City

Iowa PANS/PANDAs Legislation Communication: I have developed communication and outreach tools for Iowa legislation to mandate insurance coverage for PANS/PANDAS diagnosis and treatment.

Decorah

Connecting the Dots Family Resource Toolbox: I am working to streamline communicating localized and statewide special needs supports/ services/ resources to families in Northeast Iowa, including between agencies.

Tiffin

Increasing Transparency in SPED Classrooms: I am addressing the lack of transparency in special education classrooms by acknowledging the challenges to transparency and increasing parents' knowledge of their rights and the process to express concerns.

Iowa City

Jabez Iowa support group: This project will benefit the Latino community by offering support and resources to a growing community. We hope to start local but connect statewide.

North Liberty

Accessible Parent Support/Education for at-risk communities: I have partnered with a community liaison to offer information communicated in a culturally respectful way, and a toolkit to families with barriers to support, education and advocacy opportunities within the school district where I work.

West Liberty

Cruzando Puentes/ Crossing Bridges: I am encouraging parents to take steps to think about transition for their children. Many in the Latino community have difficulty thinking about separation from their children even if it will benefit them.

North Liberty

Juvenile Justice Awareness: I am advocating with the juvenile justice system to grow awareness of special health care needs in youth involved in the system when sentencing and releasing from treatment.

Ainsworth

Hawkeye Area Parent Empowerment Network (HAPEN): I live in a small, rural area without a lot of opportunities for education for families of special needs children. Through a parent support group, I hope to bring education on a wide variety of topics that are solicited from parents.

Fort Dodge

Paraeducator Support: I am working to increase training for paraeducators who often don't receive any special training for the kids they work with. I created a paraeducator training document from a broad array of interviews. I began with one focused on Autism and hope to do more diagnoses.

West Burlington

Family Partners of the Heartland: I created an Autism Support Group for my region with a steering committee to create a space for families to help families put the pieces together and have a place to turn to for help.

Oelwein

Sibling Support: I am addressing the lack of support for siblings of CYSHCN by creating events and activities that provide a place for siblings to socialize with other families.

Eldridge

Deaf Culture Community Gap: I want to expose my daughter's mainstream school to Deaf culture and ASL by having a Deaf adult teach sessions of ASL, getting Deaf culture books into the school library, having an ASL word/phrase of the week, and perhaps a Deaf and/or ASL club at school.

Cedar Rapids

Healthy Mind in a Healthy Body: I would like to raise awareness of improving mental health through healthy lifestyle with strict diet and exercise. I created a video documenting the success of my daughter's regime to share with parents of CYSHCN.

Oelwein

Caregiver Foundation: I am creating a platform for storytelling for caregivers to share, identify and create solutions to improve their own mental awareness and self-help.

Callendar

Adult Changing Tables: I am advocating for a changing area with adult-sized, adjustable tables that are safe and accommodating of toileting needs of families with children with disabilities. My long-term goal is to get a bill passed so that public locations will need to have at least one height adjustable adult-sized changing table.

Dike

Autism Training In-Service for schools: Teachers and associates want to effectively help children on the spectrum, however, they have expressed they feel ill-equipped to do so. Training and awareness would help staff feel more prepared and aware of what the spectrum looks like and how to address issues that may arise during the school day. I am working with my school and AEA to arrange for Autism in-services.

West Liberty

Hope for Parents: There is no training in the area of educational rights for Hispanic parents in my area. I am working with the Family Educator Partner of Mississippi Bend AEA to host an evening to raise awareness and make connections to the FEP.

Tiffin

Partnering with Special Ed Team: Our school website offers limited information for families with special needs kids. I am working with the team to add additional resource materials to the school's mental health/special needs web page. We hope to host community town hall sessions to help distribute information to local churches and organizations.

Keystone (2020)

Non-Profit Organization: I created a 501c3 to provide opportunities for personal growth and development to new and established parents and caregivers of medical and special needs children and adults.

2018

Mount Vernon

Equal Treatment at School: I developed a presentation and plan to advocate for equal treatment of students with behavioral diagnoses when considering good conduct violations that prohibit them from the physical activities they need.

Shenandoah

Southwest Iowa Autism Support Group: I convened a 13-member task force in my community to organize a sensory-friendly holiday event for families of children with ASD. I began a 5043c to sponsor continuing events.

Shell Rock

Caregiver Resilience Screening Tool: I addressed the lack of awareness among health providers about the need to identify and address the stress among parents and primary caregivers of CYSHCN. I developed a resilience scale that providers can use upon check-in at their children's appointments with referral options.

Sheldon

Northwest Iowa Parent Support Group: Knowing that the northwest corner of the state has limited resources and knowledge of state resources, I started a support group to connect special needs parents and caregivers living here. I now work as a Family Peer Support Specialist.

Des Moines

Social Media Group for Gender Nonconforming children on the Autism spectrum: I developed a social media group for youth on the spectrum, who identify as LGBTQ and their allies. I work as a Family Navigator.

Carroll

Parent Support Group: I started with an existing parent support group that needed revitalization and planned out a year's worth of topics and guidelines for the group. I now work as a Family Educator Partner.

Des Moines

Guide for Waiver Application: I saw a need for a family-friendly guide to Home and Community-Based Waivers. I worked with partners and developed a brochure entitled "You are Not Alone" and continue to serve as a resource to families.

Estherville

Support, Empowerment and Advocacy Group: I worked with another special needs mom to develop PLEAD, a support, empowerment and advocacy group for families of children with disabilities. It is open to families in seven small communities in northwest Iowa. I now serve on the DD Council board.

Grimes

"Places to Play" accessible recreational areas: I developed a "places to play" list, a collection of inclusive playgrounds in the Des Moines area, and wrote an article about inclusive play areas for the Des Moines Parent blog. I now work for the Iowa DeafBlind Project.

Glidden

Facebook page for Iowa families of children with cerebral palsy: After my son was diagnosed with cerebral palsy, I noticed there was not a statewide organization supporting families of children with CP. I started a Facebook group (CP Parents of Iowa) and connected with a national organization (Reaching for the Stars) to spread the group's impact.

Hawarden

First Responder Safety Training: I developed a First Responder training on disability awareness, discussing how to handle situations, sensory issues, and devices applicable to person who elope. With community partners, I secured grant funding to bring Project Lifesaver to our community's rescue personnel.

Amana

Prenatal Peer Support for Parents: I developed an advisory committee, then a model of perinatal support for families facing a prenatal diagnosis and choosing to carry to term. I presented the model to my denomination's leadership for possible adoption.

Sloane

Resource Guide for NICU discharge: After my daughter's experience in the neonatal intensive care unit (NICU), I knew parents need to know about next steps. I developed a "Guide to Care for Children After NICU Discharge."

Decorah

Top 10 List of Resources: I am working to simplify the maze of services, supports and funding available to rural children with special health care needs with a simple top ten to-do list following the birth or diagnosis of children with special needs.

Cedar Rapids

Iowa Hydrocephalus Association Community Network: I partnered with the National Hydrocephalus Association to build a local network to support families and caregivers with this diagnosis. I am placing brochures with resources in local neuro offices.

Cedar Rapids

Nursing Shortage Awareness: I am working with partners and legislators to raise awareness of the shortage of home health nursing services in our state.

Dubuque

Autism Connections Group: I collaborated with partners in my area to educate professionals about autism services to encourage them to share these resources with families they serve.

Iowa City

Parent Panel on Waivers for Families: I planned a panel of families with experience obtaining and using waivers to share with other parents in a resource fair setting.

Iowa City

Support for Families of children with mental health needs and learning disabilities: I collaborated with our school's administration and student advocate to increase social supports for children with disabilities in our local elementary school.

Oelwein

Early ACCESS digital story: I created a digital story about our experience missing the needed referral to early intervention services in hopes that health care providers will ensure that less children go without needed services.

Riverside

Bullying Protection in Schools: I created Special Needs and Vulnerable Children Bullying social media material. I met with other families and legislators to amend the Iowa bullying law to better protect children with special needs in schools.

Des Moines

Website for Autism Resources in Central Iowa: I created a centralized resource for families after diagnosis in hopes families will connect more quickly to recreational information and thereby grow a support network. Families cite each other as their best resource of information.

Des Moines

A-NOD for Situational Awareness: I am developing a protocol with vehicle stickers and law enforcement training to assist children with sensory issues when encountering law enforcement or rescue personnel.

Clinton

Teacher Resource Folder on "Invisible" disabilities: I developed one pagers on invisible disabilities to share with teachers in our local schools, to equip them to serve children with more uncommon diagnoses.

Dewitt

Pediatric Hearing Aid Advocacy: I worked to increase awareness of the issue and to find a legislator that would be willing to prepare and sponsor legislation that would require insurance companies to cover pediatric hearing aids.

Council Bluffs

Visual Aids for Schools: I worked with my local elementary school to reduce barriers for children with visual field impairment so they could safely navigate their school.

Dubuque

Community-based Integrated Employment: I worked with partners to create a video that shared our story to raise awareness with Iowa Vocational Rehabilitation and families about integrated employment.

Maquoketa

Epilepsy Awareness: I worked with the Epilepsy Foundation to ensure resource material gets distributed to families and caregivers who need it.

Glenwood

Infographic for Teachers: I created an infographic template families can use to share information with teachers about diagnoses, child's likes and dislikes, and how to help when child is at school.

Waverly

Mental Health Waivers and Residential Placements: I worked with partners to raise awareness of the loss of waiver supports when a child is placed in residential care for mental health treatment and returns home, only to begin again on the two year wait list.

Cedar Rapids

Transition Services Awareness: I worked with a volunteer board to streamline awareness of services for families of the Cedar Rapids School District using social media, web and email.

Dubuque

Paraprofessional Autism Awareness: I worked with parents to introduce the strengths quest program to my local school's paraprofessional team.

Iowa City

LGBTQIA+ Awareness: I made a video to raise awareness among peer support specialists and social workers about people who have diverse sexual orientation, gender identity and gender expression.

Coralville

All about Me: I created a template parents could fill out about their special needs child to share with school personnel at the start of the school year with information about diagnosis, triggers, and how to gain success. Especially helpful for substitute teachers.

Fort Dodge

Autism in College: I worked with partners to develop a program to educate college personnel about ways to assist youth with high-functioning autism to be successful in college.

Hudson

AMBUCs Bikes: I started a local AMBUCs chapter that provides adaptive bikes and trykes to children with physical disabilities and did a local news story on our son's tryke.

Vinton

Parent Representation for FEPs: I worked with my local AEA and its Family Education Partnership program to develop a simple communication tool to get parents more engaged with the AEA and school district in the IEP process.

Independence

Medical Student Sensitivity Training: I researched possibilities of implementing sensitivity training with UIHC doctors in training to equip them to deliver diagnosis and information to parents.

Pella

School Wheelchair Access: I worked with my local school to improve restroom access to students who use wheelchairs during after school activities.



Stead Family
Pediatrics

Iowa Family Leadership Training Institute

For more information or to apply for our next cohort
visit www.chsciowa.org/iflti



Check out our YouTube channel!