



IOWA FAMILY
LEADERSHIP
TRAINING INSTITUTE

Community Service Project Look Book

A look into 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 project during the course of this 6 week training, which is based on community need at the time of admittance to the program.

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 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. A seasoned family leader is provided as a one-on-one mentor 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 CYSCHN. The training teaches participants to lead advocacy activities and to work with partners and stakeholders to implement a community service project.



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.

Mt. Pleasant

SE Iowa social media website: My site educates people about Autism, shares available resources and services, and events/activities that are ASD friendly, including various languages, especially Spanish, as well as advocate for challenging behavior services in SE Iowa.

Johnston

Finding the Friendship Village: I am working with partners to identify possible pathways for social interaction and community building with the goal of developing true friendship with similar or neurotypical peers.

Marion

Experiences with School Administration when CYSCHN 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 paras 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 have 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 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 some 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 CYSCHN.

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.

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 or 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 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.

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 until (NICU) I knew parents need to know about next steps. I developed a "Guide to Care for Children After NICU Discharge".

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.

Decorah

Top 10 List of Resources: I am working to simplify the maze of services, supports and funding available to rural children with special healthcare 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 2 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.



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