

Utah Parent Center

2023 Annual Report



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Mission

The mission of the Utah Parent Center (UPC or Center) is to help parents help their children, youth and young adults with all disabilities to live included, productive lives as members of the community.

We accomplish our mission by providing accurate information, empathetic peer support, valuable training and effective advocacy based on the concept of parents helping parents.*

*The term parent is broadly defined to include anyone serving in that role.



Leadership

Executive Director Joey Hanna

Associate Director Esperanza Reyes

Fiscal Manager Sherrie Wignall

Development Director Jennie Dopp

Executive Assistant Cassandra Shaw-Myers

Letter from our Executive Director

Dear Friends,

The 2023 year was marked by challenges and opportunities. Our organization has shown incredible creativity and commitment to serving individuals and families experiencing disabilities across our great state.

Our accomplishments in the past year are a testament to the dedication of our team, the generosity of our supporters, and the resilience of the communities we serve. Some of the key achievements of 2023 include:

- Adding additional programs to our array of training offered at the Utah Parent Center, such as sibling workshops and healthy relationships training.
- Increasing our formal partnerships to more broadly serve the needs of the community.
- Reaching more individuals with vital and timely information than ever before.
- Strengthening our Governing and Advisory boards.
- Celebrating with our community in our first annual Fall Family Festival and talent show.

None of our achievements would have been possible without the unwavering support of our donors, staff, and community partners. Your commitment to our mission and the community that we serve helps drive our success. I want to extend my deepest gratitude as both the director of the Utah Parent Center and as a parent of a young adult living with Autism.

In conclusion, and as we look forward to the future, we will assess our goals with input from all of our stakeholders and remain committed to furthering opportunities for people in our community living with disabilities and special healthcare needs.



Serving the Commuity

The Utah Parent Center is the main resource and training Center for all disability-related information across the state. Our four main focus areas are **educational needs**, **healthcare needs** (both physical and mental), **transition services**, and **community access**.

Funding for our center comes from generous donors, community partners, and federal and state grants. Although we continue to grow substantially each year, we can only reach a fraction of the families in need.

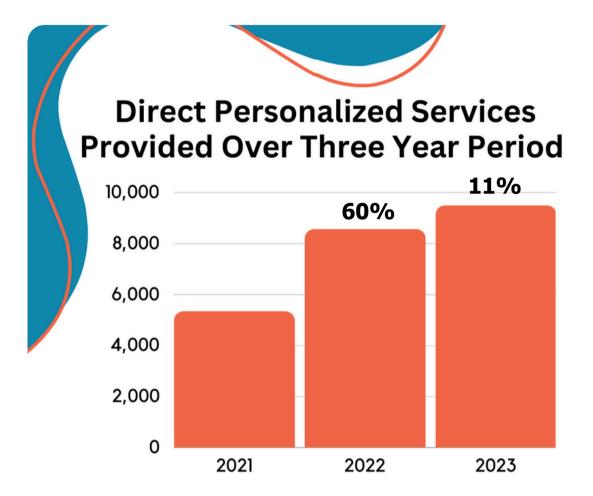
UPC staff work directly with families across Utah daily, including some in crisis. Our goal is to reach families in the early stages of their child's life so they will have the tools they need across the child's lifespan to be successful. All children deserve to be loved, understood, and included.



Our strategic plan includes methods of reaching more families early in their journey. <u>Click here</u> to support our important mission and become a champion for Utah children with disabilities and special healthcare needs.

Your Support in Action

Thanks to increased outreach efforts and support from generous donors and community partners, the UPC expanded capacity resulting in a **71%** growth in services provided by phone, in person, or through email over the past three years.



In 2023, the UPC successfully engaged with **549,311** individuals through various channels such as web views, phone calls, emails, workshops, and outreach initiatives. Despite this achievement, and based on the Kem C. Gardner and Department of Health and Human Services data, Utah has an estimated 864,120 individuals with disabilities who stand to benefit from the services offered by our Center. Through ongoing collaboration with state, foundation, and community support, our commitment remains strong in addressing this gap. We are dedicated to reaching the remaining 45% of people who may not be aware of the UPC's invaluable free services.

Program Outcome Summary



The UPC provided direct personalized services to **9501** individuals by phone, in person, or through email to **4760** unique individuals.



UPC projects provided in-person and virtual training at **264** workshops and presentations to **5,856** participants.



The UPC participated in **189** outreach activities, displays, and orientations that impacted **13,170** participants.



Supported parents in **627** school and other meetings, including IEP and Section 504 meetings.



Workshop Evaluations averaged **4.7** out of 5 for meeting families' needs, providing quality information, and relevant services



26% of the families have limited English proficiency, including Spanish-speaking only, had low incomes, or lived in rural areas of Utah.



The UPC website received **524,898** views, which is an increase of 56% from 2022.

Achievements

In 2023 the Utah Parent Center received grants from generous donors such as the Miller Family Foundation, George S. and Dolores Eccles Foundation, Sorenson Foundation, Dominion Energy, the Mower Family and other private donors to support the following new programs:

Sibling Support Groups

Siblings of children with disabilities and special healthcare needs are in a unique and sometimes challenging position. This new program is designed to support children ages 8 and up who have a sibling with a disability. "Sibshops" are a supportive space <u>Click here</u> to learn more about our projects and programs.

where feelings can be processed and youth can find a support network while participating in fun activities with their peers.

Relationship Health and Wellness Training

Statistically, women with disabilities are at a higher risk of being abused. The goal of this program is to teach teens (13–17) with disabilities about healthy relationships. Session topics include:

- Communication & Decision-Making
- Types of Relationships
- Public vs. Private
- Internet and Social Media Safety
- Boundaries and Consent
- Gender Identity and Expression
- Healthy and Unhealthy Relationships

Utah Parent Center Programs

Utah Family Voices

UFV provides statewide assistance to families of children and youth with special healthcare needs as they navigate and access health care and family support services. Resources include information about the Affordable Care Act, benefits of Medical Home, emotional and peer support, customized training, newsletters and fact sheets.

Transition University

A comprehensive curriculum for helping families learn in-depth information about the transition to adulthood for youth and young adults with disabilities. Transition University takes a holistic approach and discusses topics that span all aspects of life for the youth.

Early Hearing Detection and Prevention (EHDI)

The goal of this project is to provide accurate and objective training, consultations, information and peer support to parents of children who are Deaf or Hard of Hearing between the ages of 0–3 about system navigation, including health care and Early Intervention.

Support for Families on the DSPD Waitlist

There are many families on the waitlist for DSPD services. Navigating the disability systems can be confusing and overwhelming. This program provides parent support to families entering one-time respite services or coming off the waitlist for DSPD services.



Additional UPC Programs

Parent Training and Information Project (PTI)

The Parent Training and Information (PTI) project has been continuously funded since 1983 by a grant from the US Dept. of Education. Project goals are designed to respond to the training and information needs of the parents of Utah's identified 104,005 children and young adults with disabilities in special education. The PTI program spans all of IDEA (from Early Intervention through Post-High Transition Services, 3-22 years of age) and all topics within it.

Youth in Custody (YIC) Parent Consultant

This program helps youth in custody with disabilities, as well as their guardians and/or families to navigate the justice system and be connected with education supports. Goals include:

- increasing the number of trained surrogate parents who can understand the protections in place for YIC and help advocate for their rights/needs
- connecting parents to all entities dedicated to serving these youth
- increase understanding and building relationships that will facilitate the educational needs of these children.

Family to Family Network

The Family to Family Network is a statewide parent support network run by volunteers. It is designed to educate, strengthen, and support families of persons with disabilities, especially those who are on the waiting list or are in services with the Division of Services for People with Disabilities (DSPD). Network leaders are parents of individuals with disabilities and link families to local resources, services, and disability-friendly events.

<u>Click here</u> to sign up for our next surrogate parent training and be an advocate for youth in need.

Sponsored Events

First Annual Family Festival

Thanks to community sponsors the UPC was able to hold our first annual family event, The Fall Family Festival. The goals of this event were: to bring families together so they have the opportunity to grow their support networks, educate the community on disabilities and our programs, and provide resources and a fun activity to families. <u>Click</u> <u>here</u> to see some of the event highlights and to follow us on Instagram. **Mark June 21, 2024**, on your calendar for this year's event.

Topgolf Annual Fundraiser

Thanks to all of our amazing sponsors, we raised over \$50,000 through golf bay sales, donations, and our fantastic auction. <u>Click here</u> to see the event video.

Giving Tree Program

Thanks to our community partners we were able to serve 5 times as many families in 2023 than in previous years. The UPC provided Christmas gifts to over 530 children with disabilities and their families. **Click here to see some of the highlights.**

Want to be part of our next event? Become a sponsor and help us change lives. <u>Click here</u> to learn how.

Governing Board of Directors

The board is a parent-majority board that includes parents whose children have disabilities. Board membership also includes:

- · Individuals with disabilities
- Special education professionals
- Representatives from agencies and organizations that provide service and support to people with disabilities
- Representatives from urban and rural communities
- Various other professionals

Key partnerships include the State Board of Education, Health and Human Services, as well as Utah school districts and charter schools across the state. A separate UPC Advisory Board also works with the UPC Development Team to build capacity.

George Squires, MA, Chairperson Northwestern Financial, Wealth Advisor, Retired

Eric Stoker, Chairperson Elect Utah Developmental Disabilities Council, Information Specialist, Self-Advocate

Jean Boyack, MBA, JD, Treasurer UT Division of Services for Aging and Adult Services, Program Administrator II, Legal Services Developer

Matthew Wappett, PhD, Secretary USU, Institute for Disability Research, Policy and Practice, Executive Director, Parent

Kathryn Jenkins, Board Member Entrepreneur, Parent

> UPC Board composition must reflect a parent majority board.

Susie Estrada, PhD Candidate, Board Member Utah State Board of Education

Brady Murray, CFP, ChSNC, Board Member Capstone Partners of Utah, Managing Partner, Parent

Efren Corado Garcia, Board Member Salt Lake County Mayor's Office, Diversity and Inclusion Officer

Jessica Lamb, M.Ed, Board Member Utah State Board of Education, Dispute Resolution and At-Risk Specialist, Parent

Cagney Smullin, MPA, Past Chairperson, University of Utah College of Social Work, Administrative Manager

Joey Hanna, Ex-Officio (non-voting) Member UPC Executive Director, Parent

<u>Click here</u> to inquire about joining one of our boards.

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Advisory Board 2023-2024

Sean McCarty - Portfolio Manager Mark Richards - President, Wasatch Recovery Maricarmen Ventura - Edwards Lifesciences Tanner Withers - Financial Consultant Cindy Anderson - Parent Advocate Kyle Hepworth - Partner, Tanner LLC Jonathan Groberg - Partner, Northwestern Mutual Mark Durrant - Partner, Dorsey & Whitney, LLP Brooke Barragan - Owner, Brookey Bakes, Parent Kari Harbath - Parent, writer, Social Media Influencer

Youth Advisory Board

The Youth Advisory Board was created for motivated self-advocates who are of transition-age (14-22) and want to positively impact their community. The board meets monthly either in person or online on the first Wednesday of the month from 6 - 7 pm. This is a volunteer position to gain leadership experience, social interaction, and hone valuable leadership skills.

> If you're interested in joining the Youth Advisory Board please fill out the following form <u>here</u>

Rachel's Story

We are the Glad family. As a family, we have focused on volunteer work and giving back to our community. We are passionate about groups that have helped our family over the years. Nathan, now 16 years old, was born with a rare bone condition called Osteogenesis Imperfecta. This condition has opened our eyes to the need for the inclusion of those who have disabilities. Nathan has become quite the spokesperson for these organizations. While Nathan is cognitively-abled, his body is not. His physical limitations may be great, but his love for life, and desire to share happiness and goodness are far greater.

In our journey, we needed assistance and the Utah Parent Center was there for us. Over 10 years ago, we started the education journey and started working with schools to put in place accommodations and services for Nathan to succeed in the general education classroom. This was confusing and overwhelming. I was connected to the UPC, attended a few of their workshops, and learned all we could to support Nathan. The information presented by those who understand living differently was invaluable. We are so grateful to those who put the time in to help make sense of all there is to learn when caring for someone with a disability.

Looking Forward

In Utah, 1 in 4 people have a disability or special health care need and the demand for support grows each year. In addition to building center-wide capacity, the UPC's 2024 goals include:

- Growing our community partnerships to expand our reach with all
 of the Center's projects
- Continuing to ensure we are reaching traditionally underserved communities
- Continuing to find opportunities to push and move the bar on the inclusion of all people in all settings

Get Involved

You can be a champion for a child with disabilities by becoming a monthly donor at utahparentcenter.org or by helping us set your company up with an employee-giving program. You can also support us by volunteering and in-kind donations. Sign up to become a monthly donor to receive an inclusion hoodie. <u>Click here</u> or scan the QR code to support our work!



Thank You

Thank you to all of our named and anonymous donors who have shared in-kind and monetary gifts with the UPC. Because of your generosity, additional families can receive the training, information, and support they need to help their loved ones live inclusive and self-determined lives

Donors

ABS KIDS ABW Wealth Asilia Charities Autism Council of Utah Autism Friendly Homes Autism Learning Partners Bank of America Blind Mule Connected 2 Therapy COSTCO Dattilo Family



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