



DOWN SYNDROME

New & Expectant Parent Resource Guide

Additional Resources

Utah Down Syndrome Foundation (UDSF)

(801) 446-1994
UDSF.org | info@udsf.org

Utah Department of Health: Birth Defect Network

(866) 818-7096
Health.Utah.gov/cshcn/programs/ubdndownsyndrome.html
ubdn@utah.gov

Baby Watch Early Intervention

(800) 961-4226
Health.Utah.gov/cshcn/programs/babywatch.html | babywatch@utah.gov

Utah Parent Center

(801) 272- 1051
UtahParentCenter.org | info@utahparentcenter.org

Down Syndrome Diagnosis Network (DSDN)

(612) 460-0765
DSDiagnosisNetwork.org | info@dsdiagnosisnetwork.org

National Down Syndrome Congress

(800) 232-NDSC (6372)
NDSCCenter.org | info@ndsccenter.org



NAVIGATING DOWN SYNDROME
THE FIRST YEAR



Dedicated to Cooper Bowden
and the Bowden family, who
have made a difference in the
lives of so many in the Down
syndrome community.

This Is Not What I Ordered

BY JESSICA EGAN



When I placed my order I said, “Regular amount of chromosomes, please!” That’s what everyone else got and what I wanted too. They called me shortly after my order was in production and said “Great news, we went ahead and upgraded you to extra chromosomes for free! You’ll receive the extra chromosomes with your completed order in nine months.”

What?! I was mad! All the other orders I had seen displayed via perfect Instagram posts did NOT have extra chromosomes. Well I decided that receiving my order with extra chromosomes was better than not receiving an order at all, so I settled in to wait for this surprise upgrade to arrive.

I have now had my order for two months and am writing this review to let others know the upgrade to extra chromosomes is amazing!! If offered, definitely take it! This picture is of the finished product and you can see the extra chromosome is so worth it—it is extra cute, extra special, and extra-ordinary!

SO MUCH EXTRA JOY. WOULD PURCHASE AGAIN FOR SURE.

RECEIVING THE DIAGNOSIS

THE FLASHBULB MOMENT

Whether you received a Down syndrome diagnosis for your child prenatally or postnatally, you will probably remember that moment for a lifetime. This experience is often referred to by parents as the “flashbulb moment” or “flashbulb memory.”

During this time, most parents feel a range of emotions depending upon how the diagnosis is delivered, the resources they receive, the support they feel, and past personal experience with individuals with Down syndrome. The following is an example of one family’s flashbulb moment.



“On December 19, 2014, our genetic counselor called with the results. We were expecting a little boy with Trisomy 21 (Down syndrome). The next few days were filled with tears. We struggled with all the feelings of guilt, fear, sadness, and inadequacy that this particular diagnosis often brings. But we resolved to learn as much as we could and to connect with parents and families of children with

Down syndrome, as well as individuals with Down syndrome themselves, in hopes of understanding what this news actually meant for our family. We were desperate for a ‘real-life’ diagnosis that we could compare to the somewhat bleak clinical diagnosis we received from the doctors and genetic counselor.

The ‘real-life’ diagnosis confirmed that, yes, this ‘new’ life would inevitably be filled with some of the challenges we had been told to expect. The ‘real-life’ diagnosis also came with something unexpected. We were told that along with the challenges, we would find more love and beauty than we could possibly imagine! We’ve found the ‘real-life’ diagnosis to be just as powerful and correct as the clinical one. Our life is hard and soft, exhausting and exhilarating, full of pain and joy. Just. Like. Every. Other. Life. Our life is not ‘normal,’ but it is ours, and it is beautiful!”

—THE MERKLEY FAMILY, LAYTON, UTAH

WHAT IS DOWN SYNDROME?

WHAT CAUSES IT?



Down syndrome is the most commonly occurring chromosomal condition that occurs when a person is born with three copies of chromosome 21 instead of two. There is no known cause and nothing you did or did not do caused it. Every year, 80–100 babies are born with Down syndrome in Utah. While Down syndrome does cause developmental delays and mild to moderate cognitive impairment, the degree varies widely by individual. “Trisomy” is a medical term for having an extra copy of a chromosome and is why Down syndrome is also referred to as Trisomy 21.

There are three different types of Down syndrome:

1. **TRISOMY 21** accounts for 95 percent of those with Down syndrome. This type occurs when each cell in an individual's body has three copies of chromosome 21 instead of the usual two.
2. **TRANSLOCATION DOWN SYNDROME** accounts for three to four percent of those with Down syndrome. This type occurs when a person has an extra part or a whole extra chromosome 21 that is attached to a different chromosome rather than being a separate chromosome 21.
3. **MOSAIC DOWN SYNDROME** accounts for one to two percent of those



with Down syndrome. This type occurs when some cells have three copies of chromosome 21, but other cells have the regular two copies of chromosome 21.

To learn more visit: Health.Utah.gov/cshcn/programs/ubdn-downsyndrome.html



MYTHS & TRUTHS

WHAT YOU SHOULD KNOW

MYTH: Having a child with Down syndrome will be a burden on a family.
TRUTH: Children with Down syndrome have a variety of gifts and talents. Each individual has a unique personality all their own. They bring joy to their families and enhance the world around them.

MYTH: All individuals with Down syndrome have severe developmental or intellectual delays.

TRUTH: While most people with Down syndrome have some cognitive and physical delays, there is a wide range in their abilities. IQ is not an adequate measure of the functional status of people with Down syndrome. People with Down syndrome have great potential when given the opportunity to succeed.

MYTH: Individuals born with Down syndrome do not experience full and productive lives.

TRUTH: Individuals with Down syndrome live at home with their families, in group homes, or in homes of their own. They are integrated into the regular education system and are active participants in the vocational, social, religious, and recreational activities of the community. Many individuals will go to college, work, and lead meaningful lives.



Watch Down Syndrome 101

A short video explaining what Down syndrome is: UDSF.org/navigating-down-syndrome/definitions-myths.html.



YOU ARE NOT ALONE

UDSF.ORG

Connection with other parents who have a child with

Down syndrome can be an invaluable source of support throughout your journey. You can learn from their experiences as they provide encouragement, reassurance, and information.

The Utah Down Syndrome Foundation helps connect parents through its Newborn Care Package Program, New Parent Breakfasts, Community Groups, and Facebook group.

Newborn Care Package

For new and expectant parents, the Utah Down Syndrome Foundation (UDSF) provides care packages filled with information, both educational and inspirational, as well as gifts for the baby. These packages are designed to welcome you into our community and to help you develop a positive outlook on the future of your child with Down syndrome. They are called “care packages” because they are hand-delivered with care by a parent volunteer who has a child with Down syndrome. This parent volunteer can answer your questions and share with you, from a real-life point of view, what life is really like raising a child with Down syndrome.

New Parent Breakfast

New and expectant parents and grandparents are invited to attend UDSF's quarterly New Parent Breakfasts. These breakfasts provide an opportunity to connect with other new parents and to hear from professionals on topics related to raising a child with Down syndrome.



Request a Newborn Care Package and learn more about the New Parent Breakfasts at UDSF.org/programs/new-parent.html.

Community Groups

UDSF's Community Groups provide quarterly activities to help families connect with other families who have a child with Down syndrome. Some examples of activities include summer swim parties, holiday get-togethers, Mighty Steps for Down Syndrome walks, and much more. To find a community group where you live, please visit UDSF.org/programs/community-groups.html.



Facebook Groups

Join UDSF's Facebook group “Utah Down Syndrome Foundation” where you can ask questions, learn from others' experiences, and find the necessary resources for Down syndrome near you.



In addition to UDSF's Facebook group, many parents join the Down Syndrome Diagnosis Network's Facebook communities. These communities are not located in Utah, but they are online communities that are specific to your child's age. To join go to DSDiagnosisNetwork.org.

PARENTING A CHILD WITH DOWN SYNDROME

WHAT TO EXPECT

Raising a child with Down syndrome may not be easy, just like raising any child is not easy. However, connecting with other families who are also raising a child with Down syndrome, finding the right resources, and building a team of family and friends to support you, makes the journey easier and enjoyable.

While raising a child with Down syndrome can mean additional health issues as outlined by your doctor, developmental delays compared to typical children, and additional financial expenses, each child with Down syndrome is unique, special, and has different abilities and challenges. Most children with Down syndrome can read, write, run, play sports, ride a bike, go to school, dance, and much more.

The most important thing you can do in raising a child with Down syndrome is to provide them with a loving home where they can learn and grow.

To learn more about what families in Utah have to say about raising a child with Down syndrome, please visit [UDSF.org/Navigating-Down-Syndrome/At a Glance](https://UDSF.org/Navigating-Down-Syndrome/At-a-Glance).



ADOPTION

MAKING AN ADOPTION PLAN



Some parents, after educating themselves about Down syndrome and talking to other parents about what it is like to raise a child with Down syndrome, find the challenge of raising a child with disabilities too difficult for them or their circumstances. These parents may choose to place their child with a loving family through adoption.

The National Down Syndrome Adoption Network (NDSAN) specializes in helping parents make an adoption plan. The NDSAN has a registry of families who are approved and licensed for adopting children with Down syndrome. To learn more, please visit NDSAN.org.



YOUR CHILD'S DEVELOPMENT

THINGS TO KNOW

Utah's Baby Watch Early Intervention

All children (ages 0–3) with developmental delays or disabilities qualify for services through the Utah Department of Health's Baby Watch Early Intervention Program. Baby Watch's Early Intervention Program is mandated by the federal Individuals with Disabilities Education Act (IDEA). Services are provided by local agencies and take place in the child's natural environment (home, child care, etc.) and may include the following depending upon the child's needs:

- service coordinators
- child development specialists
- speech-language pathologists
- registered nurses
- occupational therapists
- physical therapists
- social workers
- hearing specialists
- vision specialists

The initial evaluation and assessment is free. Once enrolled, monthly program fees are determined on a sliding scale based on income and family size. Many families qualify for services at no cost.

HOW IT WORKS

1 Referral

A parent/guardian or professional is concerned about an infant or toddler's development, and contacts Baby Watch or a local EI program to request a FREE evaluation.

2 Evaluation & Assessment

A local EI program conducts a comprehensive evaluation and assessment of the child's development and the family's needs and concerns.

3 Eligibility Decision

The child may be eligible for services based on medical diagnoses, test scores, or clinical opinion. Children who are not found eligible may be evaluated again in 6 months.

4 IFSP Meeting

The family of an eligible child meets with the EI team to create an Individualized Family Service Plan (IFSP) that contains the goals for that child and family for the next year.

5 Service Visits

The EI team provides services as outlined in the IFSP, typically in the family's home or in a community setting.

6 Periodic & Annual IFSP Reviews

The team reviews the child's IFSP as needed through the year, at least every 6 months. The IFSP is updated each year at the annual review meeting.

7 Transition

As the child approaches their third birthday, the family and local EI program prepare for special education preschool and/or other community-based services.



To make a referral for your child, please contact the local Early Intervention provider for your area. A list of these providers and their telephone numbers can be found at UtahBabyWatch.org.



Feeding Your Baby

Breastfeeding your baby with Down syndrome is not only possible, but it provides important benefits to both mother and child. Learn about the possible obstacles as well as the solutions to breastfeeding your baby with Down syndrome through Motherhood International.

Learn more at Motherhood International:

MobiMotherhood.org/helping-babies-who-have-down-syndrome-learn-to-breastfeed.html



Taking Care of Your Infant at Home



The following QR code links to a one-pager containing tips for taking care of your infant with Down syndrome at home.

UDSF.org/caring-for-your-infant-with-down-syndrome.html



Milestone Markers



Children with Down syndrome typically have some **delays** in the different areas of development. On average, most children with Down syndrome reach their developmental milestones about 1.5 to 2 times later than other children. The following link is a chart of potential milestones from the National Down Syndrome Society.

NDSSorg/resources/early-intervention/

YOUR BABY'S HEALTH

HEALTH CARE CHECKLIST

Utah does not have a Down syndrome clinic where doctors specifically treat individuals with Down syndrome. Instead, parents find a pediatrician that they trust and use a health care checklist specific to Down syndrome to assist in their child's care. Such a checklist can be found at MedicalHomePortal.org and is a good reference for both you and your pediatrician. Take this checklist when you visit your child's physician. Keep a copy for your records and one in your child's medical chart.

MedicalHomePortal.org/link/5217



FINDING A PEDIATRICIAN

Intermountain Primary Children's Hospital



GENERAL CONTACT: (801) 662-1000
IntermountainHealthcare.org/primary-childrens

Primary Children's Hospital provides care in more than 60 medical and surgical pediatric specialties, and more than 800 providers all specializing in pediatrics. Search their website for a provider near you.

University Of Utah Children's Health Services



GENERAL PEDIATRICS: (801) 581-2205

SPECIALTY CLINIC: (801) 213-3599

Healthcare.Utah.edu/pediatrics

The University of Utah Children's Health Services provides a long list of pediatric services at University of Utah Health locations throughout the Mountain West and in collaboration with Primary Children's Hospital, to care for children from infancy into adulthood.

Parent Recommendations



The Utah Down Syndrome Foundation's closed Facebook group, Utah Down Syndrome Foundation, is the place to ask parents who have a child with Down syndrome for their pediatrician recommendations.



MEDICAL SPECIALISTS

Pediatric Cardiology



(801) 213-3599

IntermountainHealthcare.org/primary-childrens/programs-specialties/heart

The Heart Center at Primary Children's Hospital provides complete pediatric cardiology services.

Congenital heart defects (CHDs) are common among infants with Down syndrome. The American Academy of Pediatrics (AAP) recommends that every baby born with Down syndrome be evaluated by a pediatric cardiologist within one month of birth. This recommendation includes those infants with no evidence of CHDs on prenatal tests or examination. AAP also recommends that an ECHO be completed within the first week of life. Although, many times it will be performed prior to discharge.

Moran Eye Center/University of Utah

(801) 581-2352

Healthcare.Utah.edu/moran/ophthalmology/pediatric/

The Moran Eye Center provides eye exams, diagnosis, treatment, and surgical options for complex eye disorders in children.

Infants with Down syndrome are at increased risk of eye and vision disorders. Many of these eye problems can be treated if discovered at an early age. The American Academy of Pediatrics recommends that children with Down syndrome be examined by a pediatric ophthalmologist by six months of age with follow up exams once per year or more if needed.



Medical Genetics—University of Utah Department of Pediatrics



(801) 213-3599

Medicine.Utah.edu/pediatrics/genetics

The University Of Utah's Pediatric Medical Genetics provides genetic counseling and consultation for individuals of all ages. If Down syndrome (Trisomy21) or any other chromosome changes are found by prenatal testing, the family should receive counseling to explain the issues and provide support for the family.

MEDICAL FAMILY SUPPORT

Intermountain Healing Hearts

IntermountainHealingHearts.org/

Healing Hearts provides support for families of children and adults with congenital heart defects and childhood onset heart disease in Utah and the Intermountain West. Support includes hospital visits, events, activities, internet and phone visits, and bereavement support.



PIP Program

Parent Infant Program for the Deaf and the Hard of Hearing Through the Utah Schools for the Deaf and the Blind

USDB.org/programs/deaf-and-hard-of-hearing/parent-infant-program-pip-for-deaf-and-hard-of-hearing-children/

The PIP program helps deaf and hard of hearing children with their language development so they are preschool ready. PIP works directly with Utah's Baby Watch Intervention. Services are free and are based on a hearing evaluation.



HOW TO FINANCIALLY PROVIDE FOR YOUR CHILD'S CARE

A common question that parents ask when they receive a Down syndrome diagnosis for their child is, "How will we financially support and care for our child?" There are financial assistance programs available throughout the community, state, and nationally that can help cover the costs of raising a child with Down syndrome.

Utah's Medical Home Portal

The Utah Medical Home Portal helps parents navigate the financing of their child's healthcare. This site explains the financial programs available and their qualifying requirements.

UT.MedicalHomePortal.org/living-with-child/funding-your-childs-special-needs/financing-your-childs-healthcare



FEDERAL RESOURCES

SSI/SOCIAL SECURITY



(800) 772-1213
[SSA.gov/disability/](https://ssa.gov/disability/)

WHAT IS IT? Supplemental Security Income (SSI) for Children is a federal income supplement program that is funded by general tax revenues, not Social Security taxes. If you qualify, it provides monthly cash payments to meet the basic needs of food, clothing, and shelter for your child who has a physical or mental disability. It is another way to get Medicaid. Most children with SSI qualify for Medicaid.

WHO QUALIFIES? You can start the qualifying process by calling and scheduling an intake appointment. The Social Security Administration looks at how many people are in your family and family income. If you qualify by income, your application goes to a medical determination group, to see if your child meets their definition of medical severity. Down syndrome is one of the conditions that meets this criteria. If you qualify, you will receive monthly monies and be eligible to receive Medicaid. You have to start a Medicaid application after you get SSI. To learn more about SSI, visit [SSA.gov/disability](https://ssa.gov/disability/) and select Benefits For Children With Disabilities on the menu to download the benefits booklet.

HOW DO I APPLY?

1. Start the application process by calling (800) 772-1213 to schedule an intake appointment, which is usually a phone interview. SSI for Children can not be applied for online.
2. The process can take 3 months or more.
3. When approved, contact Medicaid and let them know your child has SSI and you want to apply for Medicaid, ABD (Aged, Blind, Disabled).
4. If you are denied SSI, ask about the appeals process.



STATE RESOURCES

MEDICAID



(801) 538-6155
Medicaid.Utah.Gov/apply-medicaid/

WHAT IS IT? This is a federal program that is administered by the state to primarily help cover medical costs. Medicaid also covers other programs such as food stamps, childcare, and/or financial assistance.

WHO QUALIFIES? Medicaid looks at how many people are in your family, family income, and the age of the child to qualify. Medicaid has several different ways to qualify depending on your circumstances.

HOW DO I APPLY? You can apply for medicaid online, in person, or by mail.



ADDITIONAL STATE RESOURCES

Medically Complex Children's Waiver



1-800-662-9651, option 5
Medicaid.utah.gov/ltc-2/mccw

WHAT IS IT? The Medically Complex Children's Waiver provides medical assistance to medically complex children. Children enrolled in this program will have access to respite services, as well as traditional

Medicaid services.

WHO QUALIFIES? Eligibility for the program is based ONLY on the child's income and assets, not the parent's. Children who meet the following criteria qualify:

1. Between the ages 0–18.
2. Have three or more specialty physicians.
3. Have three or more organ systems involved in their disability.
4. Are not meeting age-appropriate milestones for their activities of daily living; includes eating, toileting, dressing, bathing, and mobility.
5. Children who have a SSI Disability Designation through the SSA or a disability determination by the State Medical Review Board.

HOW DO I APPLY? Applications for the Medically Complex Children's Waiver will be accepted online, via fax, or mail during open application periods as funding permits.



Children's Health Insurance Program (CHIP)



1-877-KIDS-NOW
Chip.Health.Utah.gov/

WHAT IS IT? CHIP is a state health insurance plan for children who do not qualify for Medicaid and do not have any other health insurance. CHIP is administered by the Utah Department of Health. Doctor and hospital visits, dental care, prescriptions, hearing and eye exams, and mental health services are all covered by CHIP.

WHO QUALIFIES? Children under 19 who are not covered by other health insurance, are U.S. citizens or legal residents, and meet the income guidelines.



HOW DO I APPLY? Apply for CHIP online or mail an application anytime.

Utah Department of Human Services



(844) 275-3773
DSPD.Utah.gov

WHAT IS IT? The Utah Department of Human Services, Division of Services for People with Disabilities (DSPD) serves children and adults who have intellectual disabilities, physical disabilities, brain injuries, and autism.

WHO QUALIFIES? DSPD has intake workers on staff whose primary responsibility is to work with you to determine if you or your loved one is eligible for services. You will be given 90 days to complete the intake process.

utah department of
human services
SERVICES FOR PEOPLE WITH DISABILITIES

HOW DO I APPLY? Apply online and create a MySteps account.

PRIVATE INSURANCE COMPANIES

UT.MedicalHomePortal.org/clinical-practice/care-coordination/working-with-insurance-companies

WHAT IS IT? Many families use their own health insurance to cover the cost of their child's medical expenses. If you have private health insurance, contact your representative to learn what medical expenses your insurance covers for your child with Down syndrome.

WHAT YOU NEED TO KNOW: Finding out what information your insurance provider requires for prescriptions, preauthorizations, services, nutritional or other supplies, and procedures that children with complex conditions need PRIOR to receiving the medical services is recommended so there are no financial surprises. The medical requirements, processes, time frames, and options vary by insurer. The Medical Home Portal can give you more tips and suggestions on working with private insurance companies.



MORE SERVICES

Utah Department of Health—Integrated Services



integrated.Services@utah.gov
(801) 273-2988

WHAT IS IT? Integrated Services assists families of children and youth who have special health care needs with coordinated care planning, education, and resources in order for them to make informed decisions. This may include primary and special health care, behavioral care, developmental and educational programs, financial support resources, and social services that meet their special needs from infancy through the transition to adulthood.

WHO QUALIFIES? This service is free and any family in need qualifies.



HOW DO I APPLY? There is no application process. Simply call or visit their website.

Utah Parent Center



UtahParentCenter.org
(800) 468-1160

WHAT IS IT? The mission of the Utah Parent 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.

WHO QUALIFIES? Utah Parent Center is free and available to everyone.



Bringing Hope
Opening Doors
Elevating Inclusion

HOW DO I APPLY? There is no application process. Simply call or visit their website.

Help Me Grow Utah



HelpMeGrowUtah.org/enroll-now

WHAT IS IT? Help Me Grow Utah is an information and referral helpline that provides developmental screenings, gives parents ideas to support their child's development and learning, and offers emotional support to parents who are pregnant or just had a baby.

WHO QUALIFIES? Help Me Grow Utah services are virtual, free, and available to any Utah parents that are pregnant and/or have children 0–8 years of age.



HOW DO I APPLY? Enroll by filling out a form online.

Head Start Preschool



UtahCA.org/head-start

WHAT IS IT? Head Start (ages 3–5) and Early Head Start (ages 0–3) Preschool is a free program that provides high-quality education, healthy meals, medical and dental screenings, and support for the whole family to prepare a child for kindergarten. Head Start programs serve Salt Lake and Tooele Counties.

WHO QUALIFIES: Children ages 0–5 whose parents or caregivers make 100 percent or less of the federal poverty level. Children with disabilities are still eligible if parents make more than the federal poverty level.

HOW DO I APPLY? Applications for Head Start and Early Head Start Preschool are accepted year-round. Complete an easy online application and then schedule your phone interview.



National Association for Child Development



NACD.org | email: scheduling@nacd.org
(801) 621-8606

WHAT IS IT? NACD is an international organization based in Ogden, Utah that provides an individualized assessment of and tools for your child to help them reach their developmental and educational goals.

WHO QUALIFIES? Assessments are made on a triannual basis. They include an online application followed by an interview.



HOW DO I APPLY? Fill out an online application at NACD.org/get-started





KEEPING IT ALL TOGETHER WITH A CARE NOTEBOOK

Medical Home Portal Care Notebook

MedicalHomePortal.org/living-with-child/after-a-diagnosis-or-problem-is-identified/caring-for-children-with-special-health-care-needs/managing-and-coordinating-care/care-notebook

In caring for a child with special health care needs, families get information and paperwork from many sources. The care notebook is designed to help organize the information in a central place to assist both families and providers.

Your Mental Health



Healthcare.Utah.edu/hmhi/programs/crisis-diversion/#utahcrisisline
(800) 273-TALK

WHAT IS IT? Provided by the University of Utah Huntsman Mental Health Institute, the Utah Crisis Line is where you can go to get help during a mental health crisis. If you are struggling to find ways to manage a difficult, emotional situation and need help, the Utah Crisis Line is here to provide compassionate support.

WHO QUALIFIES: Callers of any age and with any mental health issue may reach out for help. Multi-lingual services are available.

HOW DO I APPLY? Call 1-800-273-8255 (TALK). These services are available 24 hours a day, 7 days a week, 365 days a year at no cost to you.

