

ARE YOU NEW TO IDAHO?

NEW TO A DIAGNOSIS?

AT A NEW STAGE IN YOUR CHILD'S LIFE?

EXPERIENCING SOMETHING UNFAMILIAR?

LOOKING FOR MORE INFORMATION?

DO YOU FIND YOURSELF ASKING, "NOW WHAT?"

YOU DON'T KNOW WHAT YOU DON'T KNOW!

START HERE: A GUIDE TO UNDERSTANDING ALL OF THE AREAS OF ASSISTANCE THAT IPUL CAN PROVIDE TO YOU AND YOUR FAMILY WHO ARE RAISING A CHILD WITH A DISABILITY OR SPECIAL HEALTH CARE NEED IN IDAHO.

IDAHO PARENTS UNLIMITED (IPUL)

MISSION

IDAHO PARENTS UNLIMITED SUPPORTS, EMPOWERS, EDUCATES, AND **ADVOCATES** TO **ENHANCE THE QUALITY OF LIFE** FOR IDAHOANS WITH **DISABILITIES** AND **THEIR FAMILIES.**

VISION A FAIR OPPORTUNITY FOR ALL!

WHAT IS IPUL?

Founded in 1985, **IDAHO PARENTS UNLIMITED, INC.** (IPUL) is a statewide organization which houses the Idaho Parent Training and Information Center, the Family to Family Health Information Center, Idaho Family Voices, and IPUL Arts.



IPUL EDUCATION: The Parent Training and Information Center ensures that parents of children with disabilities receive training and information on their rights, responsibilities, and protections under the Individuals with Disabilities Education Act (IDEA) to develop the skills necessary to cooperatively and effectively participate in planning and decision making relating to early intervention, educational, and transitional services.



IPUL HEALTH: As the State Family Voices Affiliate and the Family to Family Health Information Center, IPUL assists families in making informed choices about health care by providing training, information and resources to families of children with special health care needs.



IPUL ARTS: Creative Access Artist in Residence Program and Work of Art. IPUL empowers and engages people with disabilities in the creative process through opportunities which are fully inclusive, educational, and participatory. IPUL Arts connects teaching artists with students both with and without disabilities in Idaho schools and community centers through our Creative Access Artist in Residence program ensuring children and youth have access to high-quality arts education. IPUL Arts also houses the Work of Art program to provide pre-employment skills to youth with disabilities through a unique and collaborative design thinking process.



IPUL'S SCOPE OF WORK

WHAT WE DO:

Provide individual assistance to families through calls, emails, and in-person meetings

Provide options that you may have to resolve any individual issues

Present monthly training workshops and webinars on a variety of topics

Provide special request workshops at community events and/or conferences as well as for parent or professional groups

Advocate for systems, programs, policies, and rules that have an impact on Idaho families

Provide effective advocacy training and information for families and youth to best advocate for themselves.

Provide Parent Leadership Development training annually to build on a growing list of parent mentors who can amplify our work across the state.

Provide scholarships to parents to attend conferences or events related to your child's disability. Provide arts education through our in-school/ community center residencies and Work of Art Programs

Listen and provide support

WHAT WE DO <u>NOT</u> DO:

Advocate on behalf of an individual child or family

Attend IEP meetings

Tell you what you should do

Provide legal assistance

Endorse or promote specialty care providers, legal services, or schools/districts

Provide general parenting training (ie, court ordered parenting classes)

Provide 24-hour crisis services (we are not a crisis agency)

Provide routinely scheduled art classes

WHO DO WE SERVE?

IDAHO PARENTS UNLIMITED works with parents, family members, and caregivers of children and youth with disabilities and special health care needs and the professionals who are a part of their lives. While our office is in Boise, we work statewide using technology, and we frequently travel to all regions of the state throughout the year. We assist families who have children of any diagnosis from birth to age 26.

Who are Children and Youth with Disabilities and Special Health Care Needs?

Children and youth who have or are at increased risk for chronic, physical, developmental, behavioral, or emotional conditions and who also require health, education, and related services beyond that required by children generally (http://familyvoices.org/ncfpp/f2fs/). To keep things simple, Children and Youth with Disabilities and Special Health Care Needs will be referred to by using the acronym CYSHCN.

68% have 2 or more health conditions

45.5% have health conditions that affect their daily activities

37.5% require specialized medical care

33.2% require mental health care

47.2% needed mental/behavioral health care but did not receive it

12% of Idaho's student population receive special education services

In Idaho, there are approximately 34,000 children ages 3-21 receiving special education services. Furthermore, an approximate 4,500 students receive services under Section 504 of the Rehabilitation Act of 1973 (access accommodations). (NCLD) https://www.ncld. org/identifying-struggling-students

This does not account for infants, toddlers, or students who may be homeschooled or in private school settings. It is estimated that one in five children are living with a disability or special health care need. Idaho Parents Unlimited provides assistance and training to approximately 5,000 families and professionals each year. Our services are always at no cost to families and are available to anyone who seeks them.

OUR GUIDING PRINCIPLES

Parents, guardians, and other interested parties who seek **IPUL's** assistance will receive, on a timely basis, accurate, culturally appropriate, understandable information and referral services on their children's disabilities and their children's rights under the laws that serve children/adults with disabilities. Additionally we will provide information on effective participation in team decision making and finding service options/opportunities to meet their children and families' needs. **IPUL's** services must be accessible to all families in Idaho, regardless of language, disability, or cultural differences.

IPUL believes in the full participation of people with disabilities and their families in all decision-making processes that affect the services their children receive.

IPUL believes that people with disabilities and their families have the right and the responsibility to be actively involved in the local, state, and national decision-making that affect their lives. To that end, **IPUL** will seek to identify and facilitate the involvement of parents of children and youth with disabilities on policy making committees and activities.

Based on established priorities, **IPUL** will participate in systemic change efforts that promote the interests of individuals with disabilities and their families.

IPUL believes parents should be informed of the options and opportunities that their children, upon adulthood, have to make their own life decisions, to the maximum extent possible. To facilitate this process **IPUL** provides the tools and resources families need to best advocate in the transition to adult service systems process.

WHAT ARE PARENT TRAINING & INFORMATION CENTERS?

Parent Training and Information Centers (PTIs) are authorized in Part D of the Individuals with Disabilities Education Act (IDEA) and are funded by the U. S. Department of Education, Office of Special Education Programs. There is at least one PTI in each state. Because they are population based, Idaho has only one, and that is IPUL. Each PTI is mandated to assist parents to better understand the nature of their children's disabilities and their educational and developmental needs;

Communicate effectively with personnel responsible for providing special education, early intervention, and related services;

Participate in decision-making processes and the development of individualized education programs (IEPs) under Part B and individualized family service plans under Part C;

Obtain appropriate information about the range of options, programs, services, and resources available to assist children with disabilities and their families;

Understand the provision of IDEA for the education of, and the provision of early intervention services to, children with disabilities; and

Participate in school reform activities.

WHAT ARE FAMILY TO FAMILY HEALTH INFORMATION CENTERS?

Family-to-Family Health Information Centers (F2Fs) are family-led centers funded by the Health Resources and Services Administration (HRSA). There is one F2F in each state, in the District of Columbia, in five U.S. territories, and three are three F2Fs serving tribal communities. Each F2F is staffed by highly-skilled, knowledgeable family members who have first-hand experience and understanding of the challenges faced by families of CYSHCN. These uniquely qualified staff provide critical support to families caring for CYSHCN, particularly families of children with complex needs and those from diverse communities.

F2Fs also assist providers, state and federal agencies, legislators, and other stakeholders to better understand and serve CYSHCN and their families.

The following content identifies the core focus areas of assistance that is provided by **IPUL** through our PTI and F2F programs. Each tab will cover a broad category of assistance, and each page will highlight the topical issues that **IPUL** can provide direct resources and training.

Special Education	Parents & Professionals
Financing for Health Services	Screening
Coordinating Care	Transition to Adulthood
Navigating Community Resources	

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IPUL EDUCATION



The Individuals with Disabilities Education Act (IDEA) is the guiding law that provides the rights and responsibilities for students who are eligible for special education services in public school settings or in certain settings for infants and toddlers.

IDEA was first passed in 1975. (At that time, it was called the Education for All Handicapped Children Act.) The primary purposes of IDEA are:

To provide a free appropriate public education (FAPE) to children with disabilities. IDEA requires schools to find and evaluate students suspected of having disabilities, at no cost to families. This is called Child Find. Once kids are found to have a qualifying disability, schools must provide them with special education and related services (like speech therapy and counseling) to meet their unique needs. The goal is to help students make progress in school.

To give parents or legal guardians a voice in their child's education. Under IDEA, you have a say in the decisions the school makes about your child. At every point in the process, the law gives you specific rights and protections. These are called procedural safeguards. For example, one safeguard is that the school must get your consent before providing services to your child.

IPUL EDUCATION

IDEA covers kids from birth through high school graduation or age 21 (whichever comes first). It provides early intervention services up to age 3, and special education for older kids in public school, which includes charter schools.

https://www.understood.org/en/school-learning/ your-childs-rights/basics-about-childs-rights/ individuals-with-disabilities-education-act-ideawhat-you-need-to-know

SERVICES UNDER IDEA: WHO'S ELIGIBLE

Not every child is eligible for special education under IDEA, and having a diagnosis doesn't guarantee eligibility.

To demonstrate eligibility for special education services, all three of the three-prong test must be met and documented. The eligibility report documents each of the following criteria:

PRONG 1: The student has a disability according to the established Idaho criteria;

PRONG 2: The student's condition adversely affects educational performance; and

PRONG 3: The student needs specially-designed instruction.

To qualify, your child must have a disability that falls under one of the 13 categories IDEA covers. They are:

Autism

Deaf-blindness

Deafness

Emotional disturbance

Hearing impairment

Intellectual disability

Multiple disabilities

Orthopedic impairment

Other health impairment (includes ADHD)

Specific learning disability (includes dyslexia, dyscalculia, dysgraphia, and other learning differences)

Speech or language impairment

Traumatic brain injury

Visual impairment, including blindness

However, having one of these disabilities doesn't automatically qualify a child under IDEA. To be eligible, a student must:

Have a disability and, as a result of that disability...

Need special education to make progress in school

IPUL provides assistance regarding the following special education topics:

Child Find

Evaluation

Eligibility

Individualized Education Program (IEP) Development

Accommodations/Adaptations

Least Restrictive Environment (Placements)

Related Services (Supports, Interventions, Transportation, Health Plans, etc.)

Dispute Resolution

Behavior Plans

School Discipline

Parent/Student Rights (Procedural Safeguards)

Transition to Adulthood

504 Plans*

*504 Plans are made available to students who have a disability but who do not need specialized instruction. These plans identify accommodations a student may need to access the general education curriculum as required by the anti-discrimination law The Rehabilitation Act of 1973.



FINANCING FOR NEEDED SERVICES

There are many options that a child may have to pay for needed health services such as health insurance or Medicaid. Parents frequently ask **IPUL** about application processes and eligibility criteria. We can provide answers to those questions as well as provide training and assistance in all of the following topical areas:

Medicaid (Including Katie Beckett, EPSDT, Waivers, Buy-ins, etc.)

Children's Health Insurance Program (CHIP)

Social Security Income (SSI)

A State-Funded Financing Program

TriCare/Military

Health Exchange (Yourhealthidaho.com)

Other Public Health Care Financing program

Private Insurance Program

School-based Program

Donations/Grants/Foundations

Prescription Assistance





CARE COORDINATION

This is also known as "Accessing a Medical Home." A medical home is something like a "home base" or your health team. Your primary care physician or clinic serves as the team lead to your child's specialty needs and provides coordination of services. **IPUL** can assist in helping locate information and resources on any of the following topical areas:

Child Development
Life Course
Nutrition
Healthy Weight
Physical Activity
Sexuality
Primary Care
Specialty Care
Immunizations/Vaccines
Medical Tests
Therapy Services
Medications
Durable Medical Equipment (DME)
Supplies (diapers, formula, etc.)
Oral Health
Mental/Behavior Health
Assistive Technology
Record Keeping/Care Notebooks
Care Coordination
Cultural Competence
Interpreters/ASL



NAVIGATING COMMUNITY SERVICES

Finding and navigating community services is probably the most common area of assistance families are searching for. Because **IPUL** is a statewide organization, we can help you to locate any of these types of services throughout Idaho. Some services and supports are in every community while others are found at the state, regional, or national level. Contact us for your specific needs and we'll help you through the maze.

Community Relationships & Resources

Disability-Specific Information

Family Support

Basic Needs (food, clothing, etc.)

Housing

Home/Vehicle Modification

Utilities

Home Care

Respite

Child Care

Parenting/Foster Care/Out of Home Placements

Special Needs Planning

Legal Services

Transportation

Recreation

Cultural Brokering

Social Skills

Bullying/Violence

Safety & Injury Prevention

Substance Abuse

Hospitals/Clinics

Pet Therapy/Service Dogs

Immigration/Citizenship

Disability Awareness

Disaster Planning

PARENT & PROFESSIONAL PARTNERSHIPS

Our children do best when families and professionals have the tools they need to work together. **IPUL** can provide tip sheets, training, workshops, and other resources on the following topics:

Communicating w/ Providers

Family Centered Care

Learning Opportunities

Parent Leadership Development

Family Collaboration with Professionals

Mentoring

Systems Involvement

Title V (Maternal & Child Health)

Advocacy



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HEALTH CARE SCREENING

Screening for conditions or obtaining a diagnosis can take place at any time in a child's life. **IPUL** can offer resources regarding the various types of screening that can be performed as well as where to locate a specialist. **IPUL** can also assist in providing information to help you understand your options should you have a new diagnosis and need more information about the condition or where to get help.

Genetic Testing/Counseling

Newborn Hearing Screening

Developmental Screening

Speech & Language Screening

Vision Screening

Neuropsych Evaluation Information

Autism Spectrum Screening

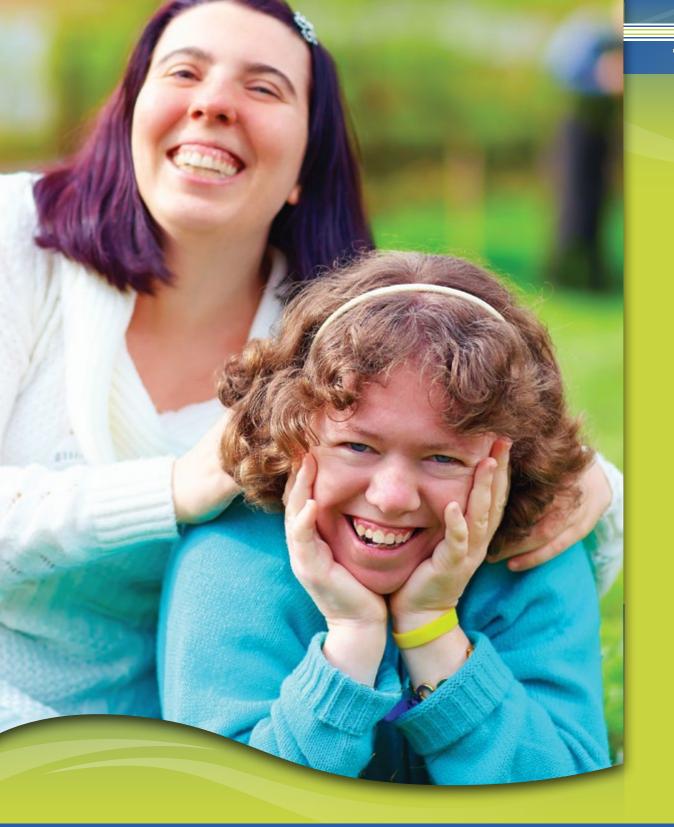
Diabetes Screening

Diagnostic Testing

Mental Health/Behavioral Screening



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TRANSITION TO ADULTHOOD

Transitioning to adulthood is big time of change in your child's life. Transition planning begins in the early teen years, and it extends until their early adult years. **IPUL** offers a wide variety of workshops, training materials, and information about this process for youth and their families. This can also include timelines that are required by various systems and agencies. Contact us if you have any questions on any of these topics.

Health Skills Training

Finding Adult Providers

Navigating Adult Services

Guardianship/Guardianship Alternatives

Special Needs Trusts

Independent Living/Housing

Self-Determination/Self-Advocacy

Person-Centered Planning

Teen councils/ leadership

Sexuality/Sexual Safety

Relationships/Socialization

Higher Education

Adult Day Care

School Transitions

Vocational/Employment

Community Involvement

Driving/Transportation

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WHO DO WE WORK WITH?

The following are just some of the agencies and organizations the **IPUL** has partnerships, grants, or contracts with both formally and informally. By collaborating extensively with different groups throughout the state, we ensure you are given every option and opportunity to make the best decisions for your child and family.

Parents, Families, Youth!

US Department of Education Office of Special Education Programs

Health Resource Services Administration

National Family Voices

Kennedy Center Office of VSA and Accessibility

Idaho Commission on the Arts

Idaho State Department of Education

Idaho Division of Vocational Rehabilitation

Idaho Department of Health and Welfare Divisions of:

Behavioral Health

Medicaid

- The Idaho Infant Toddler Coordinating Council
 - The Regional Early Childhood Committees
- Family and Community Services Children's Mental Health

Infant and Toddler Program

University of Idaho - Center on Disabilities and Human Development

Deaf Blind Project

CAC - Community Advisory Committee

Idaho Council on Developmental Disabilities

Idaho Federation of Families for Children's Mental Health

State Independent Living Council

Idaho State Rehabilitation Council

Idaho Commission for the Blind and Visually Impaired

Idaho Assistive Technology Project

Disability Rights Idaho

Western States Regional Genetics Services Network

Developmental Disability Agencies

Centers for Independent Living (LIFE, LINC, DAC-NW)

Parent Support Groups

School Districts

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