

Utah State Plan for Children and Youth Who Are Deafblind



**Special Education Services
Utah State Office of Education
Martel Menlove, Ph.D.
State Superintendent of Public Instruction**

April 2014

Utah State Board of Education

250 East 500 South
P.O. Box 144200
Salt Lake City, Utah 84114-4200

Members of the Utah State Board of Education

District 1

Terryl Warner
623 Anderson Avenue
Hyrum, UT 84319

District 2

Keith M. Buswell
1027 West 3800 North
Pleasant View, UT 84414

District 3

Michael G. Jensen
4139 South Aubrey Lane
West Valley City, UT 84128

District 4

David L. Thomas
7875 South 2250 East
South Weber, UT 84405

District 5

Kim R. Burningham
932 Canyon Crest Drive
Bountiful, UT 84010

District 6

Dan Griffiths
7302 Aeire Hill Drive
West Jordan, UT 84081

District 7

Leslie B. Castle
2465 St. Mary's Drive
Salt Lake City, UT 84108

District 8

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802 Winchester Street #100
Murray, UT 84107

District 9

Heather Groom
5586 West Timber Ridge Lane
Highland, UT 84003

District 10

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13464 Saddle Ridge Drive
Draper, UT 84020

District 11

Jefferson Moss
1668 Aspen Circle
Saratoga Springs, UT 84045

District 12

Dixie Allen
218 West 5250 North
Vernal, UT 84078

District 13

C. Mark Openshaw
3329 Piute Drive
Provo, UT 84604

District 14

Deborah G. Roberts
PO Box 1780
Beaver, UT 84713

District 15

Barbara W. Corry
1022 Cedar Knolls
Cedar City, UT 84720

Board of Regents Representative

Teresa L. Theurer
322 East 2280 North #D
Logan, UT 84341

Board of Regents Representative

Marlin K. Jensen
1500 North 7900 East
Huntsville, UT 84317

Coalition of Minorities Advisory Committee Representative

Freddie Cooper
1307 West 200 North
Clearfield, UT 84105-8601

UCAT Representative

Charter School Representative

Kristin Elinkowski
3261 Twin Peaks Drive
Layton, UT 84040

USBA Advisory Appointment

R. Dean Rowley
526 South 170 West
Springville, UT 84663

Chief Executive Officer

Martell Menlove
Phone: (801)538-7510

Secretary to the Board

Lorraine Austin
(801) 538-7515

Deafblind State Plan Committee Members

Committee Co-Chair

Christine Timothy USOE, Education Specialist/Sensory Disabilities
Leslie Buchanan USDB, Director of Deafblind Services

Members

Linda Alsop Utah State University, SKI-HI Institute
Lisa Arbogast Coordinator Law and Policy, USOE
Melanie Austin USDB, Central Division Director for the Blind
Lesly Beck Parent
Stephanie Carlson Parent
Karen Clawson USDB, Teacher of the Visually Impaired
Jeff Dean Human Resources, Utah State Office of
Rehabilitation

Jan Ferre Legislative Coalition for People with Disabilities
Darla Fowers USDB, Former Division Director Deafblind
Glenna Gallo USOE, Director of Special Education
Bill Gibson Division of Services for the Blind and Visually
Impaired, Director

Nan Gray USOE, Former Director of Special Education
Kirstin Gwilliam Division of Services for the Blind and Visually
Impaired, Former Deafblind Consultant

Todd Hauber USDB, Former Finance Director
Sue Hirase USDB, Teacher of the Visually Impaired
George Kelner Division of Services for People with Disabilities,
Director

Scott Kline Utah State Office of Rehabilitation, Consultant
Heather Kralik USDB, Teacher of the Visually Impaired
Susan Loving USOE, Transition Specialist
Vanya Maybe Early Intervention/Baby Watch, Consultant
Peggy Milligan USOE, Coordinator of Special Education
Kye Miner Parent
Cathy Nelson University of Utah, Instructor for
Linda Otte USDB Advisory Council, Former Member
Corrie Watkins Parent
Lee Weaver USDB, Teacher of the Visually Impaired
Cordie Weed Deafblind Consumer
Karl Wilson USOE, Director Title I

Deafblind State Plan Action Committees

Direct Services for the Student Age Birth through 21

1. Leslie Buchanan—Chair
2. Darla Fowers
3. Linda Alsop
4. Stephanie Carlson

Support Services for Families

1. Karen Clawson—Chair
2. Vanya Mabey
3. Kye Miner

Highly Qualified Educational Staff and Service Providers

1. Cathy Nelson—Chair
2. Leslie Buchanan
3. Linda Alsop

Coordinated Services and Resources

1. Sue Hirase—Chair
2. Vanya Mabey
3. Jeff Dean
4. Stephanie Carlson

Adequate and Equitable Funding

1. Todd Hauber—Chair
2. Karl Wilson
3. Jan Ferre
4. Darla Fowers
5. Linda Otte

Community Input into Policy Decisions

1. Lee Weaver—Chair
2. Sue Hirase
3. Bill Gibson
4. Corrie Watkins

Public Awareness System

1. Melanie Austin—Chair
2. Peggy Milligan
3. Cordie Weed
4. Kirsten Gwilliam

MISSION STATEMENT

The mission of the Utah State Plan for Children and Youth who are Deafblind is to provide a responsive, comprehensive, and coordinated system of individualized services that supports children and youth who are Deafblind and their families.

Belief Statements

The following belief statements express the underlying principles and fundamental values on which this state plan is based.

We believe that:

A full array of services must be established, be responsive, and be consistently implemented to meet the unique needs of individuals and their families.

Each individual has the right to access, participate in, and have meaningful interaction with his or her environment.

Each individual has the right to access and utilize a consistent, individualized, and functional communication system.

Direct service and technical assistance must be available within the system for the effective delivery of services.

Supports for families of children and youth are essential.

Input from and frequent feedback to parents and family members is a critical and essential element of service delivery and program evaluation.

A collaborative team approach to assessment, program development, and program implementation is imperative.

Multi-agency services and resources must be coordinated and delivered in the most natural situations and environments appropriate for each individual.

Ongoing and accessible training, education opportunities, and technical assistance are all factors which are essential for the support of families and service providers.

Implementing the state plan through interagency services and resources is essential and should be collaborative and coordinated.

Table of Contents

Members of the Utah State Board of Education	ii
Deafblind State Plan Committee Members	iii
Deafblind State Plan Action Committees.....	iv
Mission Statement.....	v
Belief Statements	vi
Deafblind State Plan.....	1
Direct Services for the Student Age Birth through 21	1
Objectives	1
The Eligibility Process Including Appropriate Assessments	1
Quality Indicators for Individualized Family Service Plan (IFSP) and Individualized Education Program (IEP) Teams	2
Overview	2
Educational Team	3
Family Priorities.....	3
Access	4
Communication	4
Social and Emotional	5
Behavior.....	5
Related Services	5
Learning.....	6
School-to-Post-School Transition.....	6
Deafblind Assessment and Coaching Team (DB ACT).....	7
Support Services for Families.....	7
Objectives	7
Person-Centered Planning.....	8
Conferences and Trainings	8
Increase Awareness for Families	8
Parent-to-parent connections.....	8
Highly Qualified Educational Personnel.....	9
Objectives	9
Pre-service and in-service education	9
Intervener Training.....	9
Recruitment and Retention of Qualified Personnel	10

Coordinated Services and Resources	10
Objectives	10
Accessibility of Instructional Materials and Assistive Technology	13
Adequate and Equitable Funding	13
Community Input into Policy Decisions.....	13
Objectives	13
Public Awareness System	13
Appendix	14
Definitions for Services Matrix	14
Additional References.....	17

Deafblind State Plan

This document is designed to improve the education and lives of Utah children and youth who are Deafblind. Deafblindness means concomitant hearing and visual impairments, the combination of which causes such severe communication and other developmental and educational needs that they cannot be accommodated in special education programs solely for students with deafness or students with blindness (Utah Special Education Rules, II.J.2.a.).

Direct Services for the Student Age Birth through 21

The USOE will provide leadership and technical assistance in the development, provision and evaluation of direct service based upon the unique needs of each child.

Objectives

- An individual who is age birth to three will receive services as identified by the Department of Health and the BabyWatch program (IFSP). If identified with additional needs, they may also receive services from the Parent Infant Program (PIP) through USDB. The service options range from home-based, community/center, to toddler/play-group classes. An Early Intervention vision and hearing specialist will work with parents and caregivers to address the child's individual developmental needs impacted by the vision loss.
- Each family of an individual who is deafblind will have access to an Individualized Education Program (IEP)/Individualized Family Service Plan (IFSP) and a targeted service coordinator consistent with the philosophy of coordinated family centered services.
- Consistent intervention services will be developed, implemented, and evaluated to meet the unique communication, developmental, academic, social, and vocational needs of each individual student (birth through twenty-one) who is Deafblind and his or her family.
- Children who are deafblind and their families will have access to an appropriate array of individualized, transdisciplinary, and direct services.

The Eligibility Process Including Appropriate Assessments

If the person is three years of age or older but younger than 22 years of age:

A combination of the following must exist:

1. Vision loss including one or both of the following:
 - A. Visual impairment that, with or without correction, adversely affects a student's ability to access visual information and to develop visual skills for educational performance. This may include partial/low vision or blindness.

- B. Functional blindness, where the physical structures of the eye may be functioning, but the student does not attend to, examine, utilize, or accurately process visual information. This may include cortical visual impairment or central visual impairment.
- 2. Hearing loss including one or both of the following:
 - A. Hearing impairment that, with or without amplification, adversely affects a student's ability to access auditory information and the development of language and communication for educational performance. This may include hard of hearing or deafness.
 - B. Functional hearing loss (abnormal auditory perception), where parts of the auditory system may be functioning, but the student does not attend to, respond, localize, utilize, or accurately process auditory information. This may include, auditory processing disorders, or auditory neuropathy/dys-synchrony (State Special Education Rules II.J.2.b(4)).

In determining eligibility for the classification of Deafblind for a person younger than age three the following information may be used:

- 1. Ophthalmological and audiological documentation;
- 2. Functional vision or hearing assessments and evaluation; or
- 3. Informed clinical opinion conducted by a person with expertise in deafness, blindness, or Deafblindness.
 - a) Informed clinical opinion shall be:
 - I. included in the determination of eligibility when documentation is incomplete or not conclusive; and
 - II. based on pertinent records related to the student's current health status and medical history, an evaluation and observations of the person's level of sensory functioning, and the needs of the family (Utah Code Annotated 53A-25b-301(2)(a)(b)).

Quality Indicators for Individualized Family Service Plan (IFSP) and Individualized Education Program (IEP) Teams

Overview

Combined vision and hearing losses create a unique and complex disability that requires highly specialized teaching approaches unique to Deafblindness and support from local special education administrators and state systems of special education. The population of students who are Deafblind is very heterogeneous. The majority of learners who are Deafblind have some residual use of either or both senses of vision and hearing. Many of these students have additional physical, developmental, and/or emotional disabilities.

Services available through the IFSP are usually provided in the child's "natural environment." Children from birth to three who are identified as Deafblind are first the responsibility of the BabyWatch Early Intervention program. As such, that child may require coordinated services through an IFSP which focuses on the child and family and the services that a family needs to help them enhance the development of their child. Each will require an individually tailored experience that should be addressed in the development and implementation of an IFSP or an IEP.

Educational Team

Due to the complexity of the needs of students who are Deafblind, it is important that the educational team works collaboratively. The education of students who are Deafblind will require input from parents and the professional expertise of a wide variety of specialists which could include:

- Regular educator
- Special educator
- Communication intervener or paraprofessional with training in Deafblindness
- Teacher of the visually impaired,
- Teacher of deaf and hard of hearing,
- Teacher of the Deafblind
- Orientation and mobility specialist
- Augmentative/alternative communication specialist
- Physical therapist
- Occupational therapist
- Assistive technology specialist
- Speech/language pathologist
- Job coach
- Personal care assistant
- Nurse, etc.
- School psychologist
- Behavior specialist

The members of the team should be selected based on the student's strengths and needs. At least one team member should have a high level of professional knowledge and skills in Deafblindness and the responsibility to educate other team members about the unique needs of the student who is Deafblind and appropriate assessment and intervention strategies.

Family Priorities

Parents or primary caregivers are the constant throughout the student's entire life and will know the student best. Parent input is vital because it provides the team with essential information that often cannot be determined through formal assessment or testing; it is essential in an individualized educational program.

Student history Information should be obtained, and may include:

- Current level of functioning, including medical issues
- Forms of communication and communication systems
- Important routines
- Socialization, including recreation
- Other services the student receives
- Coordination of services between agencies and between agencies and the families

Access

“Deafblindness creates a disability of access to the visual and auditory information about the environment (people, things, events) that is necessary for learning, communication, and overall development” (Alsop, et al., 2007). Combined vision and hearing loss impact incidental and natural learning and social relationships.

Educational programming should:

- Define the aspects of an appropriate educational environment for the student
- Provide access to the educational environment
- Provide access to the general curriculum
- Provide appropriate adaptations and modifications to the curriculum
- Provide access to communication and communication systems
- Provide appropriate and effective ways to communicate
- Provide access to appropriate technological support
- Provide optimal access to visual information
- Provide optimal access to auditory information
- Provide access to information through touch
- Provide access to people/social relationships

Communication

The ability to communicate allows people to connect with others and to establish meaningful relationships. Communication is the gateway to accessing life's experiences. Developing a student's receptive and expressive communication abilities is the key to enhancing his/her quality of life. Indeed, communication allows the student who is Deafblind to overcome isolation.

The team should do the following:

- Ensure the IEP includes goals addressing the development of communication and social relationships
- Consider the student's expressive and receptive communication skills
- Consider the role of vision, hearing, and touch in the development and use of communication
- Define the aspects of a rich communication environment for the student
- Become knowledgeable about and use the student's form of communication

- Ensure the student's peers are able to communicate with him/her
- Consider the use of augmentative and alternative communication

Social and Emotional

The combined loss of vision and hearing presents a major barrier to accessing and participating in the social and emotional environment and in the community. The student who is Deafblind is isolated from people, experiences, and things.

Programming should ensure that:

- The environment is emotionally manageable for the student.
- The staff is knowledgeable about the child and his/her communication system.
- The student has access to peers.
- Facilitate the development and maintenance of trusting, interactive relationships that promote social and emotional well-being
- A peer training and/or mentorship program is available.
- The student has an opportunity to anticipate the activities and routines of the day.
- The student has positive interactions with others on a daily basis.
- Goals and objectives include the development of social skills.

Behavior

The behavior of a student who is Deafblind should be considered from the unique perspective of the challenges associated with the lack of information. It is best to view some behavior as compliant. Data and progress monitoring may provide the kind of information to complete the decision making process about the student's behavior

Teachers and service providers should:

- Provide a predictable environment
- Help the student find desirable and effective ways to communicate
- Provide choices to help maintain a high quality of life
- Assess and functionally analyze the communicative intent of, or sensory needs met by, the behaviors in question
- When behavior is in question, include goals for improving the student's ability to communicate ideas, concerns, and strategies for providing the student with more understandable information about activities, surroundings, and expectations.

Related Services

Due to the complexity of the needs of students who are Deafblind, it is important that the educational team works collaboratively. The team may include expertise from a wide variety of specialists. At least one team member should have a high level of professional knowledge and skill in Deafblindness. This person can support other team members about the unique needs of the student who is Deafblind and about appropriate

assessment and intervention strategies. The use of a communication intervener may be appropriate for some students.

Learning

Beneficial student learning outcomes require effective programming of educational services that recognize the impact of Deafblindness on a student's unique needs and learning style. These student learning outcomes should also incorporate strategies that address the student's Deafblindness (Killoran, Davies & McNulty, 2006). Learning is best accomplished when a student has the benefits of a responsive learning environment.

Recommended strategies including:

- Utilizing ongoing technical assistance and professional development for a greater understanding of the unique needs of students with Deafblindness and to recognize and implement effective intervention and instruction.
- Considering the Expanded Core including:
 - Communication and social skills
 - Orientation and mobility
 - Compensatory skills
 - Independent living skills
 - Recreation and leisure skills
 - Vocational education
 - Visual and auditory efficiency skills
 - Self-determination based on student need
- Embedding expanded curriculum goals and objectives in the IEP.
- Aligning learning activities for all students who are Deafblind to Utah Core Standards and/or Essential Elements for numeracy, literacy, and other academic areas.
- Providing time for the student to explore and respond to objects and activities.
- Utilizing a variety of supports to ensure access to the general curriculum, such as:
 - Student specific accommodations
 - Modifications to the curriculum, if needed
 - Access skills
 - Communication interveners/paraprofessionals
 - Peer tutors/mentors

School-to-Post-School Transition

All components of educational programs should prepare students for success beyond school; at home, at work, and in the community. Educational programs should focus on college and career readiness. In order to make school-to-post-school transition planning meaningful, the IEP team is required to develop and share goals for transition to post school activities.

The IEP team should:

- Gather information through the use of person-centered planning or other appropriate methods
- Ensure that measurable, postsecondary goals are developed based on appropriate assessments at least by the age of 16, and earlier if appropriate
- Ensure that goals are based on the student's strengths, needs, and preferences
- Consider outcomes relative to communication, independent living, employment, education/training, and recreation/leisure.
- Include representatives from agencies such as Utah Division of Services for People with Disabilities (DSPD) or Vocational Rehabilitation (VR) in IEP transition planning.

Deafblind Assessment and Coaching Team (DB ACT)

The DB ACT is a neutral, transdisciplinary team available as a resource for teams serving individuals with a combined vision and hearing loss. The purpose of the team is to

- Provide Deafblind specific information as it relates to service providers from other disciplines.
- Collaboratively plan and conduct assessments.
- Collaboratively design appropriate interventions.
- Provide ongoing support as needed.

DB ACT is comprised of educational professionals with special training in Deafblindness. It was created to partner with local IEP team members, building local capacity to serve children with Deafblindness. The USOE and USDB are responsible for ongoing staffing, the training of team members, and facilitating referrals.

Support Services for Families

USOE will provide leadership and technical assistance in the development, provision, and evaluation of support services for families.

Objectives

- Identify individuals who are age birth to three who will receive services provided by the Department of Health and the BabyWatch program. If identified with additional needs, they may also receive services from the Parent Infant Program (PIP) through USDB. The service options range from home-based, community/center, to toddler/play-group classes. An Early Intervention vision and hearing specialist works with parents and caregivers to address the child's individual developmental needs impacted by the deafblindness.
- Access to an Individualized Education Program (IEP)/Individualized Family Service Plan (IFSP) and a targeted service coordinator consistent with the philosophy of coordinated family centered services will be made valuable to the family.

- Enhance family knowledge of Deafblind issues and resources through training, education, and conferences.
- Facilitate parent-to-parent networking and support.
- Promote the value of family and professional collaboration.

Person-Centered Planning

Person-centered planning is an ongoing problem solving approach to help people with disabilities plan for their future. In person-centered planning groups of people focus on an individual and that person’s vision of what they would like to do in the future. It helps those working with the individual to understand what works and what does not work.

Person-centered planning may be facilitated by agencies such as:

- Coordinating Council of Persons with Disabilities
- Division of Services for People with Disabilities
- Utah Schools for the Deaf and the Blind
- Utah Parent Center
- Babywatch

Conferences and Trainings

Various conferences and trainings are made available for families of students who are Deafblind. Information pertaining to these conferences and trainings can be found at:

www.schools.utah.gov

www.updc.org

www.usdb.org/Deafblind

www.utahparentcenter.org

Increase Awareness for Families

Relevant and current information will be provided and updated regularly through newsletters, websites, surveys, blogs, etc., such as:

- | | |
|--------------------------|---------------------------|
| • The Spedometer | Issued bi-monthly by USOE |
| • Sights and Sounds | USDB newsletter |
| • Utah Deafblind Project | Website and Family Blog |
| • E-Connections | Utah Parent Center |
| • Hands and Voices | Communique |
| • SPARKLE | SKI-HI Institute |
| • Babywatch | Department of Health |

Parent-to-parent connections

The benefits of connecting with other parents who understand the multiple challenges families face cannot be overemphasized as parents can learn from and support each

other. Parents of a student with Deafblindness will be offered the chance to connect with one another through opportunities such as:

- Utah Deafblind Project Activities
- Parent Links—Utah Parent Center
- SPARKLE—SKI-HI Institute
- Parent Infant Program—USDB

Highly Qualified Educational Personnel

USOE will provide leadership and technical assistance in the recruitment, retention, professional development, and evaluation of highly qualified educational personnel.

Objectives

- Provide effective pre-service and in-service education.
- Provide paraprofessional/communication intervener training.
- Develop and implement strategies that facilitate the recruitment and retention of qualified personnel.

Pre-service and in-service education

- Courses for a Deafblind teaching endorsement are available at Utah State University and the University of Utah. In-service is available through USOE, UPDC, USDB, and the Utah Deafblind Project.
- The university programs have outcomes based on the Council of Exceptional Children (CEC) Knowledge and Skill Standards for Deafblindness.

Intervener Training

- USDB and the Utah Deafblind Project continually update the professional development they provide for interveners employed by USDB and LEAs.
- There are two professional development online programs currently available for training interveners. One is from Utah State University and the other from East Carolina University.
- An intervener credential is available from the National Resource Center for Paraeducators at Utah State University.
- The National Center on Deafblindness (NCDB), a national technical assistance and dissemination center for children and youth who are deafblind, funded by the U.S. Department of Education's Office of Special Education Programs (OSEP), has been working on several intervener initiatives including the creation of open-access intervener training modules. Several modules are currently available with others in development. They will be available for university and state project training programs. The details of the initiatives and how to access the intervener modules are available at www.nationaldb.org.

- Intervener programs have outcomes based on CEC Specialization Knowledge and Skill Set for Paraeducators who are interveners for individuals with Deafblindness.

Recruitment and Retention of Qualified Personnel

- USDB's communication intervener training program and the employment of communication interveners provides a pool of potential Deafblind teacher specialists.
- USDB and LEAs collaborate to fill currently available positions.
- Deafblind simulations for schools, community groups, and university classes create awareness and interest in careers in the field of Deafblindness.
- Working with the National Deafblind Network on the availability of a national intervener credential for interested personnel will further opportunities for professionalism in the field.

Coordinated Services and Resources

USOE will provide leadership and technical assistance in the coordination of services and resources from various agencies.

Objectives

- Follow the guidelines and procedures in the Interagency Agreement between the USOE, USDB, and LEAs.
- Follow the guidelines and procedures defined in the Interagency Agreement between the USDB, and the Utah State Department of Health, BabyWatch Early Intervention Program. This includes the transition from Part C to Part B of the IDEA.
- Coordinate with the Department of Health and BabyWatch Early Intervention Program for individuals on an Individualized Family Service Plan (IFSP) through the PIP at USDB.
- Coordinate agency participation in any review of the Deafblind State Plan.
- Provide accessibility of instructional materials and assistive technology.
- Coordinate with Institutions of Higher Education (IHEs).

Services Offered	Birth to Three	Three to Five	Five to Eleven	Twelve to Fifteen	Sixteen to Eighteen	Nineteen to Twenty-two
Educational						
Early Intervention—Department of Health	X					
General Education			X	X	X	X
Special Education—Least Restrictive Environment		X	X	X	X	X
Utah Schools for the Deaf and Blind 504—Americans with Disabilities Act	X	X	X	X	X	X
Charter Schools		X	X	X	X	X
Private Schools	X	X	X	X	X	X
Private Preschools	X	X				
Head Start/Early Head Start	X	X				
Family Services						
Utah Parent Center	X	X	X	X	X	X
Utah Deafblind Project	X	X	X	X	X	X
SKI-HI, SPARKLE*	X	X	X	X	X	X
Early Intervention—Dept. of Health	X	X				
Utah Division of Services for Persons with Disabilities*	X	X	X	X	X	X
Religious Groups*	X	X	X	X	X	X
Head Start/Early Head Start	X	X				
Community Supports						
Division of Services for the Blind and Visually Impaired*				X	X	X
Division of Services for the Deaf and Hard of Hearing*			X	X	X	X
Church Groups*	X	X	X	X	X	X
Youth Groups			X	X	X	X
Recreation and Social Opportunities (e.g., Special Olympics)*	X	X	X	X	X	X
Health						
Clinics						
Children w/ Special Health Care Needs	X	X	X	X	X	X
Primary Children's Medical Center	X	X	X	X	X	X
Insurance						
Medicaid*	X	X	X	X	X	X
Social Security Income*	X	X	X	X	X	X
Children's Health Insurance Program	X	X	X	X	X	X
Health Insurance*	X	X	X	X	X	X
Nursing Services*	X	X	X	X	X	X

Services Offered	Birth to Three	Three to Five	Five to Eleven	Twelve to Fifteen	Sixteen to Eighteen	Nineteen to Twenty-two
Health (continued)						
Medical Home*	X	X	X	X	X	X
Utah Division of Persons with Disabilities Waivers*	X	X	X	X	X	X
Travis C. Waiver for Technology Dependent Children*	X	X	X	X	X	X
Training for Service Providers and Families						
Pre-service						
Utah State University*	X	X	X	X	X	X
University of Utah*	X	X	X	X	X	X
In-service						
Utah Parent Center*	X	X	X	X	X	X
Utah Deafblind Project	X	X	X	X	X	X
Utah State University*	X	X	X	X	X	X
University of Utah*	X	X	X	X	X	X
BabyWatch Early Intervention	X	X	X	X	X	X
National Center on Deafness*	X	X	X	X	X	X
Legal						
Guardianship					X	X
Transition						
Local Education Agency/Early Intervention	X	X	X	X	X	X
Utah Schools for the Deaf and the Blind (Including PIPS)	X	X	X	X	X	X
Vocational Rehabilitation*					X	X
Department of Services for Persons With Disabilities*	X	X	X	X	X	X
Utah Parent Center*	X	X	X	X	X	X

*Indicates this is also an adult service.

Accessibility of Instructional Materials and Assistive Technology

The accessibility of instructional materials and assistive technology for students who are Deafblind can be found at the following three providers in the state:

- The Utah State Instructional Material Access Center (USIMAC). This may include braille, large print, audio and digital alternate formats for core academic instruction for students with print disabilities. www.usimac.org
- The Educational Resource Center at USDB which provides alternate materials, resources, and equipment for students across the state who are blind or visually impaired, deaf and hard of hearing, and deafblind. www.usdb.org
- The Utah Assistive Technology Teams (UATT) provide devices and equipment through the UATT teams in each LEA www.uatt.org

Adequate and Equitable Funding

USDB will consider the needs of students who are Deafblind when preparing budgets and communicating with decision makers. Parents and other stakeholders are encouraged to advocate for adequate resources through groups such as the Utah Legislative Coalition for People with Disabilities (LCPD).

Community Input into Policy Decisions

USOE will provide leadership and technical assistance to establish and maintain a system to allow input from stakeholders into policy decisions.

Objectives

- Utilize the Utah Deafblind Advisory Panel as a forum for input from stakeholders, (e.g., families, advocates, service providers, administrators, higher education, interveners, Deafblind teacher specialists, the Utah Parent Center, and policy makers).
- Develop a Deafblind State Plan Review Committee.

In addition to the Utah Deafblind Advisory Panel stakeholders may also provide input to the USDB Advisory Council, and the Utah State Board of Education. The Deafblind Advisory Panel will create annual surveys to assure program effectiveness and assess needs.

Public Awareness System

USOE and USDB will utilize their public awareness systems to disseminate information about Deafblind issues and services.

Appendix

Definitions for Services Matrix

ADA	Americans with Disabilities Act
BabyWatch Early Intervention (BWEIP)	BWEIP is Utah's network of services for children ages birth to three with developmental delays or disabilities including assessment, service coordination development and family services.
Division of Services for the Blind and the Visually Impaired (DSBVI)	DSBVI has developed programs to help meet the needs of Utah citizens who are blind or have significant visual impairments, including vocational rehabilitation services, training, and adjustment services.
Division of Services for the Deaf and Hard of Hearing (DSDHH)	DSDHH programs include activities and services to fulfill social, recreational, and adult learning needs with barrier-free communication.
Local Early Intervention Agency	The Local Early Intervention Agency refers to the agency that provides local early intervention services. There are fifteen providers across the state.
Local Education Agency (LEA)	LEA refers to the local school districts and charter schools.
Legal Services	Legal services are available from a variety of for profit law firms. Helpful information is available from the non-profit Disability Law Center and the Guardianship Associates of Utah.
National Center on Deafblindness (NCBD)	NCBD is a national technical assistance and dissemination center for children and youth who are Deafblind. Open access intervener training modules are available through NCDB.
SKI-HI Institute (SPARKLE)	SKI-HI Institute develops materials to enhance the lives of children with special needs, their families, and their caregivers. Project SPARKLE is a program of individualized learning for parents of children who are Deafblind.

Travis C. Waiver for Technology Dependent Children

The Travis C. Waiver provides services for children who are medically fragile and who rely upon a ventilator, tracheostomy, Bi-PAP, C-PAP, or central line. The program provides the children access to Medicaid without regards to parental income or assets.

University of Utah (U of U)

U of U offers coursework specific to Deafblindness.

Utah Children with Special Health Care Needs (CSHCN)

CSHCN provides services for children who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services beyond that required by children generally.

Utah Deafblind Project

Utah Deafblind Project at the USDB provides training and technical assistance to families, service providers, community and education groups affiliated with children who are Deafblind.

Utah Division of Services for People with Disabilities (DSPD)

The DSPD promotes opportunities and provides support for persons with disabilities. Support includes community living, day services, and supported employment services. Certain individuals with special needs may qualify for benefits and funding through a waiver program called the Home and Community-Based Services Waiver.

Utah Medical Home Portal

The Utah Medical Home Portal provides information, tools, and resources to aid primary care physicians in caring for children with special health care needs and providing a medical home for all of their patients.

Utah Parent Center (UPC)

The UPC helps parents help their children with disabilities to live productive lives as members of the community by providing accurate information, empathetic peer support, valuable training, and effective advocacy based on the concept of parents helping parents.

Utah Schools for the Deaf and the Blind (USDB)

USDB provides early intervention and educational services for individuals who are deafblind in natural environments, through local LEAs, and through USDB campus programs.

Utah State University (USU)

USU offers coursework specific to Deafblindness.

Additional References

- Alsop, L., Robinson, C., Goehl, K., Lace, K., Belote, M., & Rodriguez-Gill, G. (2007). *Communication interveners in the classroom: Guidelines for teams working with students who are Deafblind*. Logan, UT: SKI-HI Institute.
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- Axelrod, C., Condon, R., Durkel, J., & Wiley, D. (1993). *Ain't misbehavin': Strategies for improving the lives of students who are Deafblind and present challenging behavior*. Austin, TX: Texas School for the Blind and Visually Impaired.
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