# Successful Transition Checklist for the First 21 Years for Children and Youth with Combined Vision and Hearing Loss

#### When diagnosed:

- Contact the Missouri Deafblind Technical Assistance Project: Have your child listed on the Deafblind Child Count. Contact Megan Burgess, 314-633-1587 or megan.burgess@msb.dese.mo.gov
- Contact a family support group- an invaluable wealth of networking, knowledge, resources and ideas
- Talk with other Families- they may have had experiences from which you can benefit
- Contact the Department of Mental Health (DMH), Division of Developmental
   Disabilities Regional Office- to determine your child's eligibility for services as soon as
   your child has been identified as "at risk" for having a disability. Regional Office is a
   state-funded agency that will coordinate person-centered services. Registration can, at
   times, be a lengthy process. Once registration is complete, it is important to keep in
   touch with your case manager to keep your case active.

Ask for the Intake Department. A family member (not a professional) must make the call.

The Regional office will accept a note requesting an application to receive services. Be sure to include the following:

- Child's name and address
- Social Security number
- Medicaid number (if applicable)
- Name of doctors, hospitals or clinics that have seen your child
- The last school your child has attended
- Any vocational training received
- Whether your child received Supplemental Security Income (SSI)
- Whether or not you can be reached by phone
- **Get medical and education evaluations** they are important to identify your child's strengths and needs.
- Begin therapy/interventions at the earliest age possible.

#### **Resources Birth through age Five:**

• **First Steps Program**- First Steps offers coordinated services and assistance to young children with special needs and their families. First Steps is designed for children, birth to age 3, who have delayed development or diagnosed conditions that are associated with developmental disabilities.

Families can contact their local First Steps office for more information by calling toll free: **866-583-2392** 

- Parents as Teachers- Parents as Teachers promotes the optimal early development, learning and health of children by supporting and engaging their parents and caregivers. For more information call: 1 (866) 728-4968
- Missouri Statewide Parent Involvement Network (MoSPIN)- The purpose of the
  Missouri Statewide Parent Involvement Network (MoSPIN) is to provide a free
  homebased program for families of children, birth through five years of age, who are
  visually impaired, including those with multiple disabilities and combined vision and
  hearing challenges. Services are coordinated with local education agencies, adult service
  providers and deafblind task forces to enhance networking and to build expertise in the
  community.

For additional information contact:
Jane Herder, Lead Parent Advisor/Family Specialist
Missouri Deafblind Technical Assistance Project
Missouri School for the Blind
3815 Magnolia Avenue, St. Louis, Missouri 63110
314-633-1582 or Jane.herder@msb.dese.mo.gov

#### **School Aged Resources:**

- Explore School options- Both public and private. Examine possibilities of integration and inclusion
- Apply for Supplemental Security Income (SSI) there are income and eligibility requirements, but it may be worthwhile to apply. Under age 18 the child's eligibility is based on the parents' income.
- Take your child out into the community-this is an excellent way for your child to learn appropriate behaviors, explore the world around them and identify positive leisure interests.
- **Give your child responsibilities at home**. Responsibilities such as personal self-care, cooking, laundry, household chores, and caring for pets as well as focusing on future job-related skills will all help foster personal independence.
- Encourage and reinforce your child's friendships, group participations and social networks.
- Explore weekend, extracurricular and summer activities- to promote independence, positive leisure pursuits and developing friendships. Camps, team events and programs offer valuable childhood experiences.
- Talk to you child about various jobs in the community.
- Foster good general health practices and physical activity- aid your child in maintaining their optimal level of health and stamina. Both general health practices and activity levels will be extended into adulthood.
- Give an allowance to begin banking, budgeting and purchasing experiences.
- Make time to tutor your child at home- Read to children who are unable to read. Teach time-telling, money, math skills, relaxation techniques, stress management and stress reduction skills.
- Be attentive to the needs of your other children as well.

- Attend workshops on assertiveness and advocacy training- Parents are their child's best advocate. There are advocacy agencies in the community available to help you with challenges.
  - -Missouri Protection and Advocacy Services
  - -No charge individual advocacy assistance when human or legal rights are violated
- Get on mailing lists- sign up to receive relevant information that pertains to your child.
- Become familiar with local resources and libraries available to you.
- Explore and subscribe to pertinent email lists, publications, and websites. There are many foundations and organizations focused on specific diagnosis's disabilities and adaptive equipment. Subscribe to receive up-to-date information and resources.
- Access respite care from your local DMH Regional Office or your local Senate Bill 40 County Developmental Disabilities Board.
- Attend workshops on Individual Education Plans (IEP) planning
  - o Missouri Parents Act (MPACT), 800-73-7634, info@missouriparentsact.org
- **Go to your child's IEP with your own specific goals**. Pay special attention that these goals are tailored to his/her needs. Invite supportive advocates and case managers to attend to collaborate with your child's education team.
- Begin estate planning. Keep your will/trust up-to-date. Keep current with related federal and state legislation. Be certain your attorney is aware of current legal precedents impacting persons with disabilities. Prior to meeting with your lawyer, educate yourself on estate planning and prepare a list of questions to bring with you.

### Age 13

- Begin formal personal future planning- set preliminary goals for supported employment, socialization and supported independent living. Missouri Deafblind Technical Assistance Project staff is able to facilitate these meetings.
  - For more information contact Megan Burgess at 314-633-1587 or megan.burgess@msb.dese.mo.gov
- Begin teaching community access skills-using telephones, ordering from a menu, basic money management for making successful transitions and purchases, locating public restrooms, keeping safe in the community, locating and attending community recreation and utilizing public transportation.
- Prepare your child for social/sexual development. Know that your child will not be a child forever. Provide understanding, support and education to your child on appropriate/inappropriate sexual behaviors, contact and relationships.

## Age 14 to 16

• **Prepare for the Transition Plan-** a big component of the IEP. Set specific individual goals.

- Include work experience goals in the Transition Plan of the IEP. If none of the existing programs meet the needs of your child, be creative and consider designing your own job training/work experience program and asking the school to assist with implementation.
- Monitor the IEP and Transition Plan- frequently re-evaluate and make revisions if necessary
- Attend workshops on transition- learn what options are currently available locally and statewide, as well as new, cutting-edge ideas that are being tried in other parts of the country.
- Age 14-15: investigate summer volunteer experiences. Use your imagination to come up with volunteer opportunities and valuable job training experiences for your teenager or young adult. Hospitals, nursing homes, adult and child day care centers, recreation centers, and animal shelters are among the possibilities. In some cases the young adult may benefit from having a "job coach" to assist them and help them become comfortable with a new task. Look to family members or other non-professionals to volunteer their time to assist the individual.
- Age 16: look into summer work experiences. Keep in mind that some summer jobs may require previous job skills and experience. If your child requires job training look for organizations in your area that provide such.
- Apply to Missouri License Bureau for Missouri ID card or driver's license at age 16.
- **Explore service providers for adults.** Research employment, skills training and residential living options available in the area you reside.
- Encourage your young adult to explore self-advocacy- speaking for him/herself, making needs and decisions known, solving problems and contributing to the community around them are all part of coming into adulthood and being their best advocate.

### At Age 18

- Apply for Supplemental security income (SSI) and Medicaid and/or Medicare- At this
  age, eligibility is now based on your child's income only. Medicaid is an important
  resource for health needs and many of the adult services including day and residential
  programs.
- Check on your private health insurance coverage for your child if coverage may continue past 18.
- Make arrangements for your young adult to register to vote.
- Assure that your youth is placed on the Helen Keller Nation Center's Register. Beth Jordan is Missouri's Representative: 450 E. Park, Olathe, Kansas 66061, 913-677-4562 or <a href="mailto:beth.jordan@hknc.org">beth.jordan@hknc.org</a>
- Make arrangements for your male young adult to register for the selective service
- Make education on-going- don't stop at age 21. Explore continuing education programs
  ad opportunities, such as technical training colleges or community colleges with
  programs to support students with disabilities. Keep reading/using audio books to
  children who can't read independently.

- **Keep in touch with case manager** invite them to IEP meetings. Discuss plans for the future and gather all specific information about the transition to adult life available.
- Revisit service providers for adults- see what new options are available for employment and residential living.
- Service Support Provider (SSP): Youth who have combined vision and hearing loss and who are able to self-advocate may be eligible for services from a SSP to help access the community. Check with the Missouri Commission for the Deaf and Hard of Hearing for which agency is responsible for these services in your area.
- Request that work experience now be a major component of the IEP
- Become familiar with Vocational Rehabilitation (VR) services and Rehabilitation
   Services for the Blind (RSB)- Apply for services while your young adult is still enrolled in
   school. Vocational Rehabilitation (VR) and Special Education share responsibility in
   preparing youth with disabilities for the transition from school to post-high school
   employment, education, specialized training and independence. Youth with combined
   vision and hearing loss are able to have dual case enrollment with both agencies.
- Revisit your Personal Futures Plan
- **Learn about the implications of guardianship** Research guardianship to determine if it necessary for your family.

# At age 20 (or year of leaving school)

- Contact Vocational Rehabilitation (VR) and/or Rehabilitation Services for the Blind (RSB) - If not already in progress, apply for a counselor and make arrangements for assessments to determine eligibility.
- Choose a vocational training or supported employment agency —Begin the process of job development with the help of VR counselor.
- Choose day program if this is your child's path
- Invite the VR counselor to attend your child's IEP- ask for their input and discuss training/employment options.
- Continue to explore service providers for adults.
- **Brainstorm for possible job leads** Take an active role in job development for your child. Get creative, use family, friends, business associates and network with community contacts to best match your child to employment that meets their future goals.
- Revisit your Personal Futures Plan
- **Investigate transportation options** learn about bus training and other services available in your area. Check with your case manager to learn about transportation services provided in your area.
- Continue to increase independence and interdependence through socialization activities
- Continue to plan for future residential placement or supported/independent living Families need to continue to take an active, assertive role in exploring available options and agencies that offer residential services as well as coming up with creative solutions to their particular situation.

- **Network**: Take advantage of the networking you have been building with other parents and advocates through support groups, schools, etc. Talk with both parents who have already found residential answers for their children and with those who are in the process of exploring various options.
- **Family Support:** Talk seriously with your own immediate and extended families about visions, goals and practical steps towards the continuing journey on the road to transition. Include your young adult in these discussions.
  - A note to families of individuals needing residential living arrangements with 24-hour "protective oversight":
    - These community placement programs are funded by the Department of Mental Health (DMH). Funding is limited for these services. Your case manager can also be a resource for social services that can make living at home easier for you and your child.
  - Notes to families of individuals who need only "planned intermittent support" and have some financial resources"
    - Your young adult will need to be able to live independently with limited assistance, and have a job or other resources to be able to pay for all or most of the rent and utilities. Your case manager should have a complete list of agencies.



The contents of this presentation were developed under a grant from the US Department of Education, #H326T130018. However, those contents do not necessarily represent the policy of the US Department of Education, and you should not assume endorsement by the Federal Government, Project Officer, Susan Weigert

