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California Deafblind Services

In this issue: Planning for Transitions Across the Ages

In this edition of reSources you will find articles and resources related to planning for transitions that occur when students move to a new class or school, age out of programs, or when school teams change throughout the years. This is such an important event in the lives of children and youth and their families and we hope what you find here will be useful to both families and educational professionals. We've pulled some archived articles and fact sheets and are sharing some new material as well. These resources include topics like considering the importance of collaborative planning for transition from Part C to Part B services; how the use of a person-centered planning approach in early years prepares a youth and young adult to prepare for their future in later years; suggestions for how to organize the smooth transition of information across school years and school personnel; and information on the topic of conservatorship and supported decision-making for those young adults who would benefit from that support. Many of the fact sheets and articles include links to external resources related to transition planning. If your team would like further consultation and resources as you make plans for and implement a transition for a child or youth who is deafblind, our CDBS staff can provide child-specific technical assistance. Learn more here: https://cadeafblind.org/ta/

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Moving Forward with the Transition to Preschool Through Collaborative Planning

— Julie Maier, *Educational Specialist* & Myrna Medina, *Family Engagement Specialist , California Deafblind Services*

"*Planning a transition takes time, communication, patience, and sensitivity to the needs and emotions of the family and their child. Planning in advance will minimize the stress caused by changes the family will experience, reduce fears of the unknown, help families to build new relationships with staff and become involved in the new program, support the child during the transition process and help him or her adapt to the new environment.*"(Lavada Minor, 1997).

Some of the more difficult and stressful periods in a family's life occur when their child is transitioning from one level of service or schooling to another. The transition from early intervention (birth to three years old) to preschool can be intimidating and scary in large part because families do not know what to expect and don't fully understand how the services and interventions for their child will change and be implemented. The unique needs of a child who is deafblind require that this transition is done with thoughtful care and in collaboration with many people, most importantly the child's family.

We have met many families over the years who have asked us, "How will I know if this is the right program for my child?" or "How can I let her new teachers and therapists know everything she has overcome and accomplished?" Others have shared their disappointment and confusion with assessment reports that don't seem to describe their child completely and seem to focus primarily on their child's limitations and deficits. Many describe their fears about moving into school systems. They did not know how they could contribute to the development of the IEP (Individualized Education Program), including during the assessment process. We would like to share our ideas for answers to those concerns and worries we hear from the families we support.

The parent's perspective

Myrna Medina, our Family Engagement Specialist and parent of a child with deafblindness, understands firsthand the emotions, expectations, and responsibilities parents experience during transition.

When we first hear the word "transition" or start talking about it, we do not know what it really means, especially when we are talking about transitions of our young children. As little as we may know about this "transition" period, we do understand that it means a move, a change, and a process. As a parent of a child with multiple disabilities, I can tell you that working with the special education system is not always an easy and pretty path filled rainbows and unicorns. However, we can help as much as possible to make these transitions as easy and smooth process as possible. I believe that this first transition in your child's educational life is the most important for various reasons.

First, parents realize and face the reality that their precious and vulnerable children will start a new journey on their educational lives. It can be a journey that starts with leaving a secure home environment or a small center-based program, which has been a welcoming family-oriented program designed to meet the unique needs of both the child and family. All of the previous services your child received from birth to 3 years old were written in a legal document called the Individual Family Services Plan (IFSP), which also considered supports and services to address the family's needs. Now the child will be transitioning to a new program that is student-focused and is guided by the Individualized Education Program (IEP) which includes goals, services, and supports to meet the child's unique needs. Parents still have an important role in any decisions made about educational services and supports.

Second, we need to remember that as our children grow older, they cannot remain in a program beyond what is appropriate, and that eventually they need to move to a different program in a new system, and the plan will

now be student oriented and not family focused. This first transition is difficult for our children, but I think it is *even harder* on parents. We are leaving behind an environment that was cozy and that welcomed us as a family. We are now moving onto a school that is bigger in size, includes more children, longer school hours and is definitely more student focused. It is one of the biggest events in our child's life and the life of our family. As parents we need to start this transition knowing as much information as possible about the process to make this scary move go smoothly. The basic information that we know at the beginning will grow with our experience. The more prepared we are, the smoother the transition. There are many strategies parents will learn and use over the years, and some of them will work and some of them won't work. It is important always to remember that we are talking about our child, their needs and well-being.

Third, the parents need to start learning the special education system and components of IEP process such as parents' rights, assessment processes, important time lines, special education acronyms and terminology, roles and responsibilities of service providers, just to name a few. It's true that any transition can be very frightening due to the uncertainty of what lies ahead. One of the best things to do to help overcome this fear and uncertainty is to be prepared, ask lots of questions, and expect answers.

We must realize that we are human beings and will make mistakes, but also remember that we are equal partners in the educational decision-making process (even though it may not seem like at the beginning). Yes, it is true the professional service providers know more than you do about special education and services, but it is also true that as the parents we know our child best.

Finally, during any transition or any time we are discussing our child's rights or our own parental rights, we need to play the role of an "advocate". We become our child's voice, but we must remember that the most important role we have to play is to be our child's advocate and not forget the focus is our child's education. Sometimes we parents confuse what "*we need*" or "*we want*" with what "*our child needs*" to succeed. We must stay focused on sharing with the team what our child needs. That is our right and responsibility as parents — to advocate for our child's needs, not our own.

The need for careful and thoughtful transition planning

Children who are deafblind have unique educational needs and determining a child's skills and educational support needs can be a challenge for a new team. There are few reliable standardized assessments that are normed or appropriate to use with this population. Educational professionals also need to look very closely and thoroughly at so many areas of the child's skills and development beyond just the areas of vision, hearing, and cognition which requires time and considerable consultation and collaboration to get it right. For most children with deafblindness, especially those with additional disabilities or medical/health issues, a collaborative team approach is needed to ensure accurate assessment results since so many areas of development are interconnected. Finally, the fact that the transition to preschool is a huge event in the family's life cannot be overlooked and care and consideration must be given to the family's experiences with their child and early intervention services up to this point. The family should be encouraged to actively participate in the assessment in an informed and supported manner.

Three key practices to utilize at this important transitional point in child's life are **1)** discover the family's story, which will reveal so much important information about the child as well; **2)** use a collaborative assessment approach in order to gain the most complete and accurate profile of this child and their needs; and **3)** engage in interactive discussions about the child's development, skills, and support needs with other team members, important members of the child's family, and current early intervention service providers. We have seen these types of practices contribute to comprehensive plans that have led to successful transitions for many preschoolers.

Specific practices to utilize Early Intervention providers (sending team)

- Let families know what to expect during the transition process to preschool and start planning together about key information to share with school team.
- Give information to families about upcoming trainings about IEP process or preparing for transition to preschool.
- Assist the family with connecting to local support services (e.g., family support groups, family resource centers, service providers you may know in the child's local school district, state deafblind project staff).
- Share with the family the ways their participation in their child's program and services may differ in a center or school-based program rather than a home program. Offer strategies for ways they can get involved at their child's new school or program and effective ways to communicate between home and school.
- Share the most recent assessments and progress reports with receiving team.
- Assist the family in putting together a packet of information, or a personal profile or photo story about their child and family. (See articles on Creating a Photo Story and Personal Profile in this edition of *reSources*)

School district (receiving team)

- Consider and appreciate the enormity of the transition for this family.
- Provide clear verbal and written explanation of the assessment process and IEP meeting and service placement discussion.
- Strive to collaborate with the other service providers assessing the child so that the final assessment report provides an accurate, strength-based portrait of this child, their current and emerging skills, and specific support needs.
- Hold parent training activities (e.g., "Learning About the IEP Process") and make strong efforts to reach the families with children under the age of 3.
- Contact and consult with local deafblind specialists or service providers with experience serving children who are deafblind during the initial assessment process and the transition into a new school program.
- Don't forget to gather input from the family. Ask them about their family, their child, and their hopes and goals for their child.
- Conduct assessments in natural settings that are familiar to the child.
- Provide the family with information about programs and services and supports that are available, including visits to see programs that are offered.

Family

- Develop a personal profile, or "All About Me" book/ packet, or Photo Story about your child and family. (See articles on Creating a Photo Story and Personal Profile in this edition of *reSources*)
- Attend family training activities on the IEP process and roles and responsibilities of families.
- Ask other parents who have already gone through this transition for support and suggestions.
- Ask district staff to consult with deafblind specialists and the child's current intervention service providers.
- Reach out to local deafblind specialists for advice and support.
- Contribute as much information as you can to the specialists conducting the assessments. The receiving school agency will likely ask you to complete written questionnaires, or they may want to interview you in person. Let each specialist know what you have shared with the other specialists.
- Write up a list of the services and supports you think your child needs and be prepared to present it at the meeting. Prepare a statement to make at the beginning of the meeting about your child and family and what you hope to gain from the meeting.
- Visit the receiving school or program, possibly with your child and one of early intervention service providers.
- Remember YOU are the expert on your child.
- It often helps to bring a photo of the child to the meeting to keep everyone focused on this unique child.
- We hope families and service providers will find these suggestions helpful. The success of this first transition is so significant for each child and family. Successful transition planning builds trust, leads to positive outcomes for children, and provides teachers and service providers with the plans and tools they need to meet a child's unique educational needs. A successful first transition builds the foundation for future successful transitions.

References:

Minor, L. (1997). Planning transitions to preschool. In D. Chen (Ed.) *Effective practices in early intervention.*

Preparing for Adulthood Starts from the Beginning

— *Janelle Dowling, Educational Specialist,* & Julie Maier, *Project Coordinator, California Deafblind Services*

Why is it important?

Many families and individuals will transition from middle to high school and realize that they are only four years away from their post-secondary program. Four years can disappear in the blink of an eye and, all of a sudden, there are about a million things to plan for and think about with very little time to do it. As we know, individuals who are deafblind require more time to process and plan for upcoming change. They need more time to understand their options, consider their needs and preferences, identify necessary accommodations and support services, and communicate about these things with their teams. Often, families with deafblind children also need more time to consider all the factors involved in a transition and really think about their hopes, dreams, fears, and action plans. There are so many other things that are happening every day in the here and now. When and how can we expect individuals and their families to plan for this crucial transition out of school age and into adulthood?

Instead of approaching this topic when children turn 16, the age an Individualized Transition Plan is required in an IEP we should consider how we can guide families to start thinking about their child's future as an adult from the very beginning of their educational programming.

Family Centered Planning

When families begin to receive Part C services and partner with early intervention service providers, they are invited to participate in various information gathering processes, which are centered around the family's training and support needs and hopes and dreams for their child. Early interventionists may use particular tools and curriculum that are designed to support the family to recognize their family's strengths, capacities, and circles of support while also starting to identify their young child's likes and dislikes, modes of communication, sensory channels, and potential skills.

Learning to observe, reflect and record their child's strengths, interests, and accommodation and support needs while their child is very young and sharing this information with others sets an important foundation for developing a vision and goals for their child's future. The family members are looking toward a fulfilling future for their child and can model these expectations, hopes, and goal-setting for the child. Planning for the transition from early intervention to school-based services when their child turns 3 years old is an initial opportunity to engage in child-focused planning which can be expanded as they age. Creating a personal profile or All About Me Book to share with their child's preschool team and completing parent interview tools like *HomeTalk* (Design to Learn) during the initial assessment period are wonderful ways for families to share valuable information about their child. *HomeTalk* is a helpful assessment tool for parents and care providers of children who are deafblind with additional disabilities. It offers them the opportunity to participate in the planning of their child's educational program by sharing their observations, perspectives and priorities.

Early-person centered planning can also be supported by including a young child who is deafblind in daily home routines and developing expectations and goals for new skills and concepts that can be learned through fuller participation in home routines. Sighted and hearing children watch and listen and for the most part incidentally learn skills and routines that increase their growing independence. Children who are deafblind need direct experiences to learn these same skills and concepts. Identifying multiple ways for your child to participate, even partially, in daily routines will promote more independence and teach the child of the high expectations you hold for them. A resource we often recommend is Parents and their Infants with Visual Impairments (PAIVI) from American Printing House for the Blind. Similar to *HomeTalk*, *PAIVI* is an easy-to-follow guide that provides family members with the opportunity to share observations about their child and their participation in daily routines and activities at home. From there, the family and early interventionists or

educational professionals can identify daily routines and develop adapted materials and simple routine plans that the family can follow to support their child's communication and daily living skills.

Another way families and early interventionists can help prepare families and individuals to think about transition age from the beginning is to gradually increase expectations for child participation in the development of their transition portfolio. This fact sheet provides a timeline for how teams can work together on this project throughout the child's life and into adulthood. If the child is participating in the development of their transition portfolio throughout their entire life, they will have a stronger sense of self, confidence in their skills, and understanding of their own abilities and aspirations.

This kind of planning and a focus on providing opportunities for children to learn about themselves and to share that information with people in their circle of support can make that transition from high school to post-secondary programming more smooth and less stressful for everyone involved. The family and the individual will be more prepared and self-determined as they enter into adulthood.

There are two additional resources in this edition of *reSources* that may be helpful in early years: ***Creating a Photo Story of Your Child to Share with the Educational Team*** and ***Personal Portfolios***

From TRANSITION Fact Sheet, Originally Published in reSources Summer 2004

Suggestions for Creating Successful Transitions from School to Adulthood

— Maurice Belote, Emeritus, California Deafblind Services

While this is not an exhaustive list of steps towards successful transitions, it represents a few of the things I've learned over the years.

Mind the gap. The subways in London remind you, as you step off the trains, to mind the gap— the space between the subway car and the platform. In the same way, mind the gap between the end of a school career and the beginning of adult services. We know that the longer the gap in services, the greater the likelihood that persons who are deafblind may not have meaningful employment, adequate housing services, and/or community access to recreational and social opportunities. For example, if you can find a permanent job placement for an individual a few months before that person would otherwise age-out of special education services, why not take it? If the IEP can be modified so that services can be provided in this new environment, all the better. But if it can't, don't regret the little bit of missed school. A seamless transition into adult services may be more important than those last few weeks of school. Of course, major transitions cannot be rushed but must be thoughtfully planned so the individual has time to prepare for the changes.

Plan early. The law states that at age 14 a student's IEP must include transition service needs and at age 16 that IEP must contain needed transition services. (Yes, even educators are confused by this wording.) Don't let this requirement be satisfied with the attachment to the IEP of a single sheet of paper with a few boxes checked. By this time in a student's lives, educational programs should be leading to clearly defined outcomes. All components of educational programs should be preparing the student for success beyond school—at home, at work, and in the community.

Does every step lead towards the desired outcome? Ask yourself at IEP meetings: does each goal and objective move this student towards a concrete and functional outcome? If a student is 20 years old and hasn't mastered tying shoelaces after years and years of trying, let it go; the student will probably be just as relieved as you are. The same goes for writing a signature, spreading butter on bread, or any other skill that has been worked on for years with little or no success. There may be other things for the child to learn that are more important, such as personal hygiene skills. Employment and housing personnel report that this is one area they would really like the persons they serve to take care of themselves—if they can. And remember the importance of cleanliness when it comes to social interactions.

The importance of social skills. Social skills are just as important—if not more important—than competence. People will put up with a lot of incompetence if you have good social skills. Think about your own experiences. Have you ever worked with someone who, although he or she wasn't the hardest worker at your place of employment, was friendly, brought fresh-baked cookies on Fridays, told good jokes, or pitched in for the office parties? Imagine that same person, who wasn't the hardest worker, if he or she hadn't contributed positively to the work environment. Stopping at the donut shop once a week on the way to work to bring a box of donuts to the office may contribute more to longevity and social relationships than performing flawless work tasks day after day.

Document everything. It is important to document everything that might someday be necessary to know. This includes tasks at which the person who is deafblind excels, their expressive and receptive communication systems, preferences and dislikes, favorite leisure time activities, etc. This documentation will be useful as video resumes and/or personal communication dictionaries are compiled. Consider the following example. A student paddles a kayak across a lake at age 16, has a great time, is good at it, and then doesn't have the opportunity to do it again for years. By the time the student is 22 years old, will anyone remember this event and the fact that kayaking might be a great recreational activity for this person? They will if it has been documented. This can be accomplished with videos, photographs, journal entries, or any other method that works for those involved.

The "readiness model" might impede success. There was once a belief that students had to earn opportunities for jobs, living situations, etc. by demonstrating readiness. Consider the following example. A student wants a work experience placement at a plant nursery watering plants. Under the readiness model, the student would have to prove his or her readiness by successfully watering plants in the classroom for a period of time, which would then be followed by a trial placement watering plants on the school grounds. If all of this goes well, the student would then graduate to watering plants at an actual nursery. The problem with the readiness model is that the student may never get past watering in the classroom for reasons that have nothing to do with the ability to water plants. Perhaps the student is bored with the classroom because he or she has spent too many years there. The student may be loud and unfocused while watering in the classroom, and the assumption is that the student will behave in a similar way out in the real world. But given the opportunity to do this job in a natural environment, the same student might very well succeed. The student's behavior might have been saying "I'm sick of the classroom", but in a real environment with natural motivators and consequences, the student may pleasantly surprise the doubters.

It's all about who you know. It's true that much of what we have in life — our jobs, apartments, significant others — we discovered through someone we know, or through someone who knows someone we know. For example, when considering work experience placements for students, think about people you know who have small businesses such as restaurants, hair salons, offices or warehouses. When looking for apartments, think about people you know who live in desirable buildings and may know of unpublished vacancies, or people you know who work as property managers or real estate agents. Even if it's a friend who knows someone, have him or her make an initial call on your behalf. It will make your subsequent call much easier and will probably make the person more interested in what you have to say because they know you're a friend of a friend. This is something we need to learn from people in the private sector who practice this well: never underestimate the power of personal contacts and connections.

Get the relevant facts. Make sure you know everything there is to know about the individual who is deafblind: likes, dislikes, activities in which they excels dreams, fears, social connections, and anything else that might impact future success. Gathering this information might be accomplished though processes such as personal futures planning, MAPS, person-centered planning, etc. Parents, siblings, extended family members, neighbors, and former teachers are all vital sources of useful information. These same people are also vital sources of information about interpreting the individual's wishes if the person has limited formal communication skills.

Transitions Between Educational Team Members:
Consistently Sharing Information

— Janelle Dowling, Educational Specialist, California Deafblind Services

The Challenge: Many families and educational teams spend a lot of time putting together important information about their deafblind students to share with teachers, service providers, peers, and other team members. This might take the form of a personal passport, an "All About Me" presentation, a website, a shared drive folder, a binder, a communication dictionary, etc. Unfortunately, just as often, that information does not then actually get passed on to new team members when they join, to new teachers when the student moves up, or to new peers when they are introduced. The beautifully curated information gets lost in the piles of paperwork or gets left in a box of student materials and moved through classrooms without another look.

We reached out to a few California educators who shared that some of the biggest difficulties they encounter in developing strong collaborative relationships within their teams are related to lack long term retention of team members. Many times, new team members are joining after the school year has started or service providers are rotating more frequently within a school year. Another common challenge for teams is the lack of time in their schedules or space in their caseloads to communicate and plan together with other service providers and the families. For larger teams, one of biggest challenges they are facing

is around coordination and the need for one main point person to hold and disperse important information and keep everyone on the team organized and in the loop. So, what can we do to alleviate these challenges and to ensure smoother transitions for everyone.

A Solution: In considering the work we have done with educational teams and based on feedback from California educators, we think there are three key elements teams should have in place to support this smooth transition between service providers; **1)** a team leader, **2)** welcome processes, and **3)** consistent updates.

Team Leader: There should be someone on the child's team who can coordinate information sharing, guide team members to seek more training or technical assistance when it's needed, and maintain open communication with the family, the student, and the team members. We sometimes refer to this person as the "champion" for the student. They are someone who is dedicated to understanding deafblindness and how it affects the student, helping all team members increase their own understanding of the child's unique needs, and helping the family and the student develop trusting, respectful, and meaningful engagement with their team members. This person should be organized and collaborative and someone who will work with the student for more than one year (if possible). Teams report that when there is a clear leader or coordinator on the team, information is shared more consistently, collaboration is more effective, and the student is ultimately able to make more progress.

Welcoming Process: Once someone is assigned to work with the student, they can receive a message from the team's leader which includes three to five steps they should take to learn about the student and their team.

Below are some examples of what this process might include:

EXAMPLE 1:

- **File Review:** Includes IEP documents AND Student Summary (ex; Personal Passport, Student Profile, All About Me) AND a letter from the family.
- **Deafblindness Introduction:** Share 1-2 resource links for basic information about deafblindness that will help the person better understand the student. Resource Example: "***An Overview of Deafblindness***": https://www.nationaldb.org/media/doc/Overview_of_Deafblindness_Infographic_JUL2022_a_1.pdf
- **"Welcome to My Team" slideshow:** Includes pictures or video clips of team members and information about their role and one thing they love about working with the student, pictures and/or video clips of the student greeting someone or introducing themselves, etc. If it is appropriate for the student to review this slideshow with the new team member, that would be an excellent way for them to engage in the welcoming process.

EXAMPLE 2:

- **File Review:** Includes IEP documents AND Transition Portfolio
- **Deafblindness Introduction:** Share 1-2 resource links for basic information about deafblindness that will help the person better understand the student. Example: "An Overview of Deafblindness": https://www.nationaldb.org/media/doc/Overview_of_Deafblindness_Infographic_JUL2022_a_1.pdf
- **Communication/Symbol Dictionary Slideshow:** Includes pictures, video clips, and explanations about the student's expressive and receptive language systems, the best ways to interact and communicate with them, and important information about touch cues and object cues used throughout their day.
- **Family "Letter":** Parents, siblings, and the student have teamed up to write a short letter or make a slideshow sharing some things they want every team member to know about the student right away and some helpful information about their home/family life and their hopes and dreams for their child. This should

be short and serves as a way for the family to communicate with team members early in their welcoming process without feeling like they need to re-tell their story or re-state important details multiple times.

Updates:

1. **Team Leader reminds** team members at the beginning of the school year and again a month or two before the end of the school year (or before they transition off of the team) to review the information sharing systems (profile, website, slideshows, binder, etc.) and update as needed.

2. **Encourage Families** to participate in updates by sharing recent photos, video clips, or refreshing the notes related to family/home life or parent input.

3. **Student Involvement:** If the student learns the importance of sharing this information with new people, they will take on more of the responsibility and this will build self-determination and awareness. A student can have a binder to hand someone or a card with a QR code for the digital system that they give to the person when they first meet. They can share a short presentation slideshow, send an email, or participate in a "getting to know you" conversation with new team members. The student should engage in this step of the process as much as appropriate using an accessible format for sharing the information.

4. **One way for teams to include students** in keeping their information up to date is to embed it in the classroom curriculum. This can be tied to narrative writing standards in K-12. Students can also update these documents or systems as part of preparation for participating in their IEP process.

5. **Ongoing Communication:** Many teams find that a group chat (e.g., google chat, text group, etc.) and/or a shared drive, website, or digital folder are very useful in keeping the entire team in communication.

If educational teams can work together to develop these simple systems, it will ultimately save time and increase effectiveness and continuity for the student's instruction and growth. The three elements should be individualized to meet the student's and team's needs. The systems should be in a format and sharing style that works for the family, the student, and the preferences of the team members. Processes like these are important to meet the unique needs of deafblind students who often have multiple teachers and service providers who change frequently. If you would like support to develop an information system for your team, please contact us. We'd love to assist your team.

Developing Your Transition Portfolio

0-5 years old

Tell Your Story: Work with your family to think about the best way to tell your story.
Get comfortable: Notice what about your home, therapy, or preschool is most optimal for learning and where you can be most comfortable. Take pictures and video clips.
Communicate: Work on developing a communication system that works for you.
Start Your Toolkit: What works and what doesn't? Take notes and document examples.

5-12 years old

Tell Your Story: Create a portfolio to share information with friends, teachers, therapists, etc. Learn about yourself, participate in creating the portfolio and sharing it.
Make Connections: Build connections and learn to play, interact with your environment, and engage with your surroundings. Develop relationships with service providors.
Communicate: Learn to share about yourself, make choices and ask for help. Start a sign dictionary as needed
Update your Toolkit: What works, what doesn't? Take notes and document examples. Learn about and participate in your IEP.

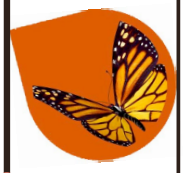
12-16 years old

Tell Your Story: Update and share your portfolio and information about yourself with your community.
Participate: Learn about different jobs, activities, and concepts and consider what you are good at, what you enjoy, etc. Learn about money, spending, and long term planning.
Communicate: Make choices, share your opinions, ask for help, and continue to develop and update your dictionary as needed.
Update your Toolkit: What works, what doesn't? Participate in your IEP.

16-18 years old

Tell Your Story: Share your portfolio and begin Person Centered Planning process.
Participate: Continue learning about different activities, jobs, experiences, etc. Share your opinion and learn about self advocacy and planning for your future.
Communicate: Continue to communicate about your thoughts, opinions, and needs. Share about yourself and update your system as needed/appropriate.
Update Your Toolkit: What works and what doesn't? Take notes and document examples. Participate in/Lead your IEP and PCP.

18-22 years old



Tell Your Story: Share your portfolio with new friends, classmates, coworkers, service providers.
Participate: Engage in recreation and work experiences in your transition program. Express your preferences and advocate for opportunities that are interesting to you.
Communicate: Continue and Update
Update Your Toolkit: What works and what doesn't? Take notes and document examples. Participate in/Lead IEP and PCP and create a video intro or video resume.

22+ years old

Tell Your Story: Share your portfolio with new support staff, friends, coworkers, and anyone else who might want or need to know more about you and your experiences. Keep it updated about once per year.

Created By: Janelle Dowling, MA

Personal Portfolios

also known as "Transition Portfolios"

WHY?

As parents, *you* know that there are hundreds of questions that need to be answered, millions of tiny gems of information you know and want to share about your child, and a lot of things that fall through the cracks between transitions.

As educators, *we* know that it can be incredibly difficult to have all the information we need about each of our students and when we get new students, we often have to spend a lot of time gathering information about their history, what has worked or not worked for them in the past, what experiences they've had, or other key information about their accommodations, support needs, preferences, etc. Then, we often get new support staff in our classrooms every year and have to help share all that information with them.

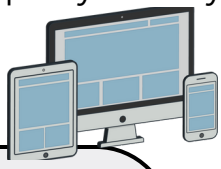
A transition (or personal) portfolio can be developed from the beginning of a child's life and is a meaningful way for them to gather, maintain, and share information about themselves, their educational and developmental history, and many other key details about who they are and how we can best support them, their families, and their goals. If this personal portfolio follows them and is updated regularly throughout their school years, it can easily become their transition portfolio and stay with them into adulthood.

This saves time, while also decreasing stress and confusion for the parents, students, and their team members and makes the transitions between programs, school years, and support teams much more smooth.

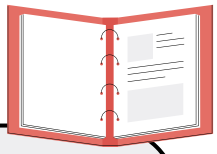
WHAT?

A transition portfolio (or a personal portfolio) is a paper or digital collection of key information, work samples, and photos/video clips that can be shared with new friends, colleagues, educators, therapists, doctors, (or anyone!) that the person will interact with on a regular basis. The information should be gathered throughout their school years and be updated at least once per year to make sure the details are accurate. As the person graduates into a new classroom, program, or job, they will be able to share information easily and quickly with anyone who needs it.

HOW?



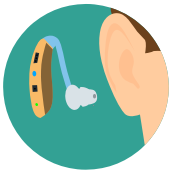
A digital portfolio can be a website, private, personalized and easy to update annually. This format can make it easy to share photos, video clips, and notes/work samples with the entire team and make it simple for the website to be shared with new team members as needed. Teams can also create a google folder (or something similar) with different files for sharing work samples, photos/videos, info sheets, etc.



If it is important to have a hands on format for the portfolio, you can use a binder and include pages, pockets, and pictures. A portfolio should be accessible for the student themselves and include a format that they can explore, participate in updating, and share as needed.








Created by: Janelle Dowling, MA

Exploring Supported Decision-Making:
An alternate path to conservatorship that supports choice and independence

— Julie Maier, Project Coordinator, California Deafblind Services

When a youth turns 18 years of age they are recognized as a legal adult with certain rights and responsibilities related to decisions about their life, including holding educational rights within their IEP, managing finances and their health care decisions, and making other important decisions about their life. This is important for families, youth, and young adults to understand as there is shift in who holds legal authority to agree to the IEP developed for that student. For young adults who are deafblind with additional disabilities and receiving additional supports to participate in their school program and community, careful thought and consideration must be taken to determine if, and to what degree, the person is able to make decisions related to their education, finances, medical care, and relationships. Preparation for the development of a plan to support this legal transition should occur well before the individual's 18th birthday.

Let's begin with a few descriptions to explain the differences between guardianship, conservatorship, and supported decision-making as implemented in California and key components of each relationship.

Guardianship: Guardianship means that an adult, other than the parents, holds the legal right to make decisions for a minor child or children.

Key components:

- Guardianship extends only to minor children (e.g. under the age of 18).
- Formal guardianship is a legal arrangement. The guardian can make legal and medical decisions. Legal guardianship takes place when the need for guardianship is longer than 1-2 months.
- Guardianship can be arranged informally, such as when another family member takes over parenting responsibilities for a short period of time. Informal guardianships are best when the guardianship is short-lived with a clearly identified endpoint. This type of guardianship is focused on ensuring the physical and emotional well-being of a child, such as daily need for shelter and food, physical or medical care, and supporting academics.

Conservatorship: A court appoints another responsible adult to act and make decisions for an adult who needs help to understand and make decisions. Conservatorship is similar to legal guardianship except it is for an adult.

Key components:

The well-being and maximum independence and autonomy for the individual with a disability is the goal of conservatorship. This legal arrangement should only be established when a less restrictive option is not possible. First consider the individual's ability to make choices and alternate ways they could be supported to make decisions about their life. Limited conservatorship can be granted, which provides the adult with disabilities with the maximum amount of autonomy and rights.

Conservator's responsibilities and rights may include all, or some, of the following:

- Make decisions about education and vocational training.
- Look at confidential records and papers.
- Sign contracts.
- Manage financial affairs.
- Give or withhold consent for most medical treatment, excludes sterilization and certain other procedures.
- Decide where the conservatee will live (does NOT include a locked facility).
- Placement at a state facility for persons with intellectual disabilities.
- Give or withhold consent to marriage.
- Control the social and sexual contacts and relationships.

Supported decision-making (SDM): SDM is a process that allows an adult with disabilities to retain decision-making capacity by choosing supporters to help them make choices and decisions. A person using SDM selects trusted advisors, such as friends, family members, or professionals, to serve as supporters who agree to help the person with a disability understand, consider, and communicate decisions.

Key components:

- SDM is less restrictive than conservatorship as the person uses supports to make their own decisions and choices about their life. The person with the disability is in charge.
- SDM looks different for everyone.
- It includes finding the tools and support to help the person understand, make and communicate their own choices and decisions.
- Supporters can be changed easily and SDM doesn't involve a court process to make the change as conservatorship requires.
- SDM is not the same as person-centered planning, however that is a tool that can be used to make decisions and engaging in person-centered planning early on can help to prepare an adult for SDM.

Families may not be as familiar with the option of supported decision-making for their adult child. The family may understandably have concerns and fears about their child's well-being, safety, health, and the consequences of decisions they may make. However, it is important to remember that these are concerns and worries that most parents have about their children as they enter adulthood, whether or not they have a disability. Being in charge of your own goals and decisions and living with the outcomes and consequences is an important part of this transition to adulthood and supporting your adult child to retain their right to make decisions about their life may be a more appropriate option to pursue. Certainly, young adults who are deafblind with additional disabilities will need guidance and support to make choices and decisions that are in their best interest and move them forward on the path toward the future they envision. This is where family members, friends, and trusted community members play an important role as either the trusted advisors the person chooses in the SDM process or people who support this path for the young adult.

The following are some important elements and questions to consider for the SDM option:

- **Take time to learn** about the Supported Decision-Making Model and talk to adults who are using this process. We've provided resources at the end of this article.

- **Have discussions with the individual.** What kinds of choices and decisions do they currently make? What additional decisions would like to make? Does the person know and recognize that everyone looks to family members, friends, and experts for advice when making decisions?

- **Identify opportunities and challenges for the individual.** What has been a barrier to decision making in the past? What supports work well and could allow them more or better decision making in the future? What aspects of the person's life offer opportunities to make decisions?

- **Identify potential supporters.** Who do they turn to for advice and help? Who are the people in the individual's life who could support the person to make decisions? What agencies and organizations can provide additional support the person needs?

- **Coordinate support:** Who holds the knowledge and skills to support the individual in coordinating their supporters and identifying what type of support they could provide (e.g. one person might support educational decisions, another finances, another health care decisions, and another with social relationships, or some supporters could serve multiple roles)?

- Work with the person and their supporters to **develop a plan identifying the people and professionals who will provide the support** for their needs that describes how and when they will provide it.

- **Create a formal documented plan:** Support the person to create a written plan or record that shows the types of support the person will receive, when, and from whom. This will ensure everyone stays organized and appropriate follow-up occurs.

Adapted from Gustin & Martinis, 2016

Individuals with disabilities, including those with deafblindness, face many societal and attitudinal barriers which have led many people to presume individuals with disabilities, especially those with high support needs, lack competency and agency and limit their rights and opportunities. There are many systems and programs in place in our school and communities to teach and support youth without disabilities how to prepare to be an informed, civic-minded, contributing citizen. However, many systems within our society do not inherently provide the accommodations and supports adults with disabilities could use to participate more independently in educational, work, and community settings and to have control over choices and decisions in their lives. Family members and educational professionals can support youth to develop self-determination skills, set goals for their future, and learn how to make good, informed decisions with supports from others. We encourage school teams and families to use self-determination curriculum and identify multiple and varied opportunities for youth to develop these skills and help them prepare to engage in supported decision-making to the greatest extent possible. Youth and young adults who are deafblind with additional disabilities deserve the right and chance to participate in and contribute to their communities as adults and supported decision-making is an effective and flexible process to help make this possible.

We have provided a list of additional resources below that can help you in the journey to learn more about supported decision-making as an option.

Relevant Resources:

Disability Rights California: Principles: Conservatorship of Individuals with Disabilities.

Undivided: Supported Decision Making 101

National Resource Center for Supported Decision-Making: Website Homepage with Resources and Tools

National Resource Center for Supported Decision-Making: California: Supported Decision-Making

The ARC of California: Supported Decision-Making Boot Camp: Training Videos and Materials

American Civil Liberties Union Disability Rights Program: Supported Decision-Making: Frequently Asked Questions

Impact: Feature Issue on Self-Determination and Supported Decision-Making for People with Intellectual, Developmental, and Other Disabilities: Making it Happen: Strategies for Supported Decision-Making

References:

Gustin, J., & Martinis, J. (2016). Change the culture, change the world: Increasing independence by creating a culture of coordinated support. *Apostrophe Magazine.*

Martinis, J. (n.d). Making it happen: Strategies for supported decision-making. *Impact Feature Issue on Self-Determination and Supported Decision-Making for People with Intellectual, Developmental, and Other Disabilities.*

American Civil Liberties Union Disability Rights Program. *Supported decision-making: Frequently asked questions.* Retrieved 11/16/23: https://assets.aclu.org/live/uploads/document/FAQ_about_Supported_Decision_Making.pdf

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Creating a Photo Story of Your Child to Share with the Educational Team

— Julie Maier, Educational Specialist, California Deafblind Services

In October 2020 during a virtual Symposium on Deafblindness our deafblind network colleague and friend, Dr. Donna Carpenter, presented about the power of sharing stories through photos and anecdotes. This is a practice the Kentucky Deaf-Blind Project uses with families to support and empower them as they introduce their child with deafblindness to a new school team. This photovoice practice was developed and researched by Dr. Carpenter during her dissertation study, *Experiences of families raising a child who is deafblind and teacher response to those shared experiences (2016)*. Her study examined the effects of several families using photos paired with audio recording to share stories about their child's journey with their child's teacher. The study outcomes demonstrated the positive impact and changes these "virtual stories" had on the teacher's perceptions of and expectations for that child.

Here is a how-to factsheet with suggestions that families and educators can use to introduce and share information about a child or youth with deafblindness.

Creating the Photo Story

- Select 10-20 **meaningful** photos of the child. These might be favorite photos of the child, photos of milestones, photos of the child with important people in their life, or the child doing their favorite activity.
- Think of the order in which you'd like to share the photos. (Note: It doesn't necessarily need to be chronological.)
- Decide on a short story or description you'd like to share about each photo and include that in an audio recording or short text accompanying the photo.

Ways to present the photo story

- Short narrated video using iMovie or similar app.
- PowerPoint or Google slideshow with text or audio narration.
- Pictello, an app to easily create stories with personal photos or videos.
- Bring photos to an IFSP or IEP meeting or team planning meeting and share descriptions in the moment.

When can Photo Stories be useful

- When a child starts in a new class or program.
- At the beginning of an IFSP or IEP meeting to remind everyone about the uniqueness of the child at the center of meeting.
- During transition planning or a person-centered planning process. Encourage and support the child or youth to help present the information.
- As an orientation activity when developing new peer connections or supports.
- To share information with new staff members or service providers.
- To promote and practice self-advocacy.

When using Photo Stories start to look for and discuss this important information

- Child's preferences and interests
- Sensory information
- Important life experiences
- Individualized supports and accommodations
- Child's and family's dreams and vision for the future

We're grateful to our network colleague, Donna Carpenter, for sharing her research and ideas with educators and families in California. If you'd like help creating a visual story for your child, the CDBS staff would be excited and happy to assist you. Feel free to contact anyone on our staff to get started.

References:

Snyder, D. (2016). Experiences of families raising a child who is deafblind and teacher response to those shared experiences. Doctoral Dissertation. Northern Kentucky University.

NEW RESOURCE! The CDBS Digital Transition Toolkit

There are so many useful resources, videos, webinars, fact sheets, and articles related to the larger topic of "Transition" and we are compiling some of our favorites into a "Transition Toolkit" on Padlet. This will be a space where families and professionals can easily find information or tools they need. The toolkit include links to resources related to Person Centered Planning, Self Determination, Preparing for Work, Preparing for Post-Secondary Education, Social Connections, Transition Portfolios and Goal Setting, and Starting Early. We hope you will go explore the toolkit and share it with your teams:

https://padlet.com/cadeafblind/transition-toolkit-to05tktq4xwiebzc

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