



reSources

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Is There Life After Special Ed?

by Kathleen Campbell

Having a person with disabilities in your family changes your life forever. Moms, dads, siblings, grandparents, extended family and friends learn to adjust, adapt and regroup from the time a child with disabilities enters the picture. Parents, especially, learn the intricacies of laws we never knew—or wanted to know—existed; terms like “early intervention”, “IEP”, and “fair hearing, please”; how to advocate for services and find support for ourselves; behavior modification strategies (for us, if not for the kids); and, to be resourceful beyond anything we ever dreamed we could be. As the years go by, we are sure that we’ve pretty much heard it all and know it all. We’ve read the books, watched the videos, gone to the meetings, figured out special ed, and learned our rights. This is, after all, survival of the...well, OK, most informed and well known at school. Nothing can surprise us anymore.

And then it happens. It happened to us ten years ago. Just when we thought we knew all of the answers, they changed the questions. Suddenly—amazingly—our son, Jason, who has developmental disabilities, became an *adult* according to the laws of nature and the State of California. It crept up on us through transition plans and discussions of “work experience”. Slowly the reality dawned that soon we wouldn’t have special ed to kick around anymore. We were entering the Twilight Zone of Adult Services! Overnight, the rules changed, and the familiar terrain that we were used to negotiating was dramatically different. New issues cropped up: agencies with different (sometimes conflicting) rules; “supported employment”, “day programs” and SSI; reliance on regional center services; college (what are the laws about modifications THERE??); conservatorship or not; “consumer choice” (*who* is making the decisions? Yikes!); and, perhaps the most basic, lifestyle

and housing. The decisions that needed to be made seemed overwhelming!

In Jason’s case, our decision was to tackle housing before he left special education at 22. This way, he wouldn’t have to make all of the big transitions at once. For over a year, we traveled the California countryside seeking out every possible adult placement. All of the options were group residences of one size or another; the nicest ones had waiting lists. None of the choices had room for both Jason and his friend, Mike, and the guys had developed a great friendship—a first for each of them. Although very limited in their communication skills at that time (now both can use facilitated communication), they let us know that they wanted to live together. Finally, as is necessary in group living, there was a lot of talk about daily “program”. We knew that road; Jason and Mike were already living in a group situation with other kids at St. Vincent. The more we looked and talked, we all realized that what Jason and Mike wanted—and what we wanted for them—was not a “good residential program” but a good *life*.

“Supported living”, a new concept to California ten years ago, was the answer for Jason and Mike. This is an option where people live in a home they have chosen (house, apartment, condo, etc.) to rent or buy, with or without roommates or housemates, and are provided the support and services they need at home and in the community to create a lifestyle specific to them. The person’s own wishes, dreams, needs and choices provide the foundation for planning the supports and services, including who will actually provide the training and/or assistance that is needed. The paid

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supports are funded through regional center and In-Home Support Services (IHSS)/Dept. of Social Services. The option of supported living was never offered to Jason and Mike. In fact, several key people pronounced them “too severely disabled” to ever live in their own home. Undaunted, we created a proposal to work with the regional center in helping Jason and Mike develop a plan. And, since we were already pushing the envelope, we decided to function as the agency, or “parent vendor”. When you’re breaking new ground, you might as well go all the way! Thanks to Jason and Mike’s tenacity (“Move! Move!”), a forward thinking regional center director, and our unmitigated audacity, Jason and Mike are currently enjoying their ninth year in their home in Santa Barbara.

They live in a four bedroom, 3 bath home near the beach. Several shopping centers, many restaurants and bus stops are within walking distance. The downtown area and City College are minutes away. They have jobs and go to classes. Two housemates live with them and are paid to provide support. All four share the rent, utilities and groceries, with Jason and Mike’s shares coming out of their SSI and (very) small wages. On weekends, housemates or other friends provide paid support. Through the variety of people providing support and the friends that they introduce to Jason and Mike, as well as their unlimited opportunities to participate in the community, there is an ever-expanding circle of friends. It is now impossible to go to any busy area of Santa Barbara or Goleta with Jason without someone saying “hi” or stopping to chat. No one is hired or fired without Jason and Mike’s approval; they are involved in interviews, weekly meetings, evaluations and other typical daily decisions. They have gained experience in making choices, and have become active self-advocates. Of course, there are still difficult days, excessive laundry and lots of coordination to make things come together. And Mike’s mom and I must constantly resist the impulse to hang kitchen curtains and re-fold the towels. But it isn’t a *program*; and, while it is not a perfect life, but it *is*, by Jason’s (typed) account, “A life with peace. It is good.”

Here are a few key points that help define supported living:

- **Everyone is “ready”.** This is different from traditional services such as independent living, where a person has to prove his readiness to live in his own home. Even people with what are considered the most severe

disabilities can succeed in their own homes with the right supports, services and training. No one can be denied supported living services by the regional center based solely on the nature or severity of their disability. Through *appropriate planning, implementation and flexibility of support*, we can make the services meet the person’s needs and wishes instead of fitting the person into someone’s pre-determined program goals. People don’t fail at living in their own homes; we fail to provide the appropriate types and levels of support at the right times.

- **Individual choices drive services and supports.** The person being supported is encouraged to make, or be significantly involved in making, the choices and decisions about his or her life, supports and services. Each supported living arrangement *should* be different from the next—by design. Circles of support, including families, often play an important role in assisting the person in making decisions and supporting those decisions.
- **Separate housing from provision of services.** In group situations, for example, the housing and services are usually provided by one entity; when irresolvable problems arise with a consumer’s services or his needs change, typically he is asked to move to another placement. In supported living, he stays in his own home, and the services change as necessary. In fact, by regulation, the provider of services (the regional center “vendor” or agency) *cannot* control the home of a person they are supporting in a supported living arrangement.
- **No licensing.** The person’s home is just that—his home. There is no community care licensing in supported living. Not having to deal with licensing gives more freedom in planning supports (for example, learning to spend time alone if that is a goal), and more time to spend on developing and utilizing true measures of the person’s satisfaction with his life.
- **Services and supports evolve and change as the person’s wishes and needs change.** Flexibility in supports and services is key in supported living arrangements. Hopefully, the person’s desires and needs *will* evolve and change in many areas of life as that person experiences growth and gains self-confidence. None of us wants a life that is stagnant.

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Supported living services must be adaptable and responsive to each individual.

- ***More opportunities for independence and individualized support.*** Even though Jason and Mike live together, we specifically planned for them to have *individual* supports. This maximizes their learning to make choices and decisions, their senses of independence and self-confidence, and their ability to have the differing types of support they want, need and have a right to receive.

The numbers of people choosing supported living as a lifestyle option are increasing. We now know many individuals who experience a degree of opportunity and independence that no one would have predicted before they were receiving supported living services. This is especially true for some of our friends with, shall we say, “severe reputations” in regards to behavior. Remember, supported living is an option available statewide to regional center clients; its availability is not dependent upon the whim, training or opinion of any one professional. As with other services, some service coordinators are better informed than others and some regional centers are more supportive than others, but all must follow the law and regulations. If you are interested in supported living, call your service coordinator to request information and/or to schedule a meeting to discuss supported living or add it to your IPP as a goal. Make sure you include an estimated timeline for moving in; you can change this if you need to later, but it helps everyone to know what your expectations and wishes are.

It may take some work to get there, but having a home to call your own is worth it. For Jason, it is freedom, independence and opportunity. For me, it is the security of knowing that he has a place to call home, that he is growing and achieving new things each day and that he is happy. And, something else—seeing Jason’s pride as we celebrate special times, such as Thanksgiving, with him as *our* host.

Our next great adventure is home ownership for Jason and Mike, and others with developmental disabilities. Many programs are becoming available to provide purchase and/or down payment assistance just for this purpose, and we have been spending quite a lot of time tracking down these resources. What better way to ensure your place in the community than become a

homeowner? Besides, we can always use more “adventure” in our lives...

We all feel fortunate to be part of Jason and Mike’s lives. It is our hope that we will, together, be able to continue supporting them as they determine their life directions and achieve their hopes and dreams.

Epilogue:

Last summer, Jason’s dear friend and housemate, Mike, lapsed into a coma and died. There was no warning, no good-bye. He was 29 years old, and we all miss him everyday. For Jason, he has lost a soul mate with whom he shared his life and home over the past thirteen years, first as roommates at St. Vincent, and later as just two cool guys living in their own place near the beach. For us, we have lost part of our family, as sure as if Mike were our own son.

There has been much grieving over this past year by many people in Mike’s life, including the other friends that shared Mike’s life—the people providing support to him each day. They were there when he collapsed; they stayed with him, talking, reassuring, making him laugh, holding his hand; advocated for him with the medical staff. They were the last people he saw, gracing them with one of his typical Mike-smiles just before he went into the coma. They comforted and cried with family members—all of us—and they carried on for Jason and our families when their hearts were breaking. They are, indeed, much more than “support people” or “staff”. These young people were truly a part of Mike’s family. They loved him, challenged him, respected him, and still grieve for him. He taught them lessons they would never have learned anywhere else. He has changed their lives.

Jason tells us through his typing that “Mike stayed as long as he could”, that “Mike’s gift to us was what he taught us about love and family. Now his lessons will shine through us. He loved us all and wants us to love each other”. In death, as in life, their connection with each other is strong. “Mike will always be my best friend. He watches over us.”

We have weathered cleaning out Mike’s room, grief counseling and memorial celebrations where we gathered to remember the wonderful, funny and not-so-funny times with him. Life does go on. But for all of us, Mike will stay in our hearts. Mike has made his mark on the world, and it is indelible. He was one of the pioneers, a successful example of unexpected independence, a valued member of his community. He has helped to pave the way for others who will come after him. I

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am grateful for the honor of having known and loved him. Our lives are certainly richer for being part of his life.

Some lessons are hard to learn. Letting go is hard. Finding that we cannot protect our children from all hurt in the world—although we knew it all along—is hard. But as difficult as real life can be, it would be worse to be isolated from the experiences and risks that provide us the freedom and opportunity to grow. This is part of the circle of life. Disability, or marching to the beat of a drummer no one else has ever heard, should not be a barrier to these powerful experiences that enrich and deepen our lives.

Mike didn't miss any of life. He had the chance to make his own decisions, chart his own course. Thank goodness we didn't wait until someone, somewhere thought he was "ready" to live in his own home and in his own community. He might have still been waiting for a life when his came to an end. We never know what tomorrow will bring.

Michael Jackson's music has always been a favorite that Mike and Jason shared. He sings a song, "Gone Too Soon", that will always remind me of Mike. "... Shiny and sparkly, and splendidly bright, here one day, gone one night. Like the loss of sunlight on a cloudy afternoon, gone too soon." Gone too soon...

Kathi Campbell (closackathi@aol.com) was a co-presenter for the most recent CDBS interactive satellite broadcast training *A Place Called Home: Creative Living Options for Individuals who are Deaf-Blind and/or Have Severe Disabilities*. She is the Director of Creative Living Options, an agency based in Sacramento.

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Our team is here to serve families and professionals of individuals who are deaf-blind, birth through age 21. Please get in touch with us if you have questions or feel we could be of assistance!

How to access our services
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Jackie Kenley, Family Specialist, ext. 21
Myrna Medina, Family Specialist, ext. 25
Gloria Rodriguez-Gil, Educational Specialist, ext. 26
Larry Rhodes, Educational Specialist, ext. 24
David Brown, Educational Specialist, ext. 22
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Fact Sheet

How To Create a Winning Video Resume

by Maurice Belote, CDBS Project Coordinator

Many individuals who are deaf-blind and/or have severe disabilities are far more capable than they may appear on paper (i.e., written reports, assessments, checklists, etc.). When seeking work experiences—volunteer, shadowing, training, or paid—some people who are not familiar with disabilities may focus more on limitations than strengths. A video resume is a great way to show potential employers that a person with disabilities has specific skills and abilities that might be a good match for a job. It isn't just employers who can use the tape; the tape might be useful when generating the support of a skeptical administrator, job coach, or teacher. While it is a good idea to start early in an individual's school career, it is never too late to create a powerful resume to support that person's transition from school to work. You are creating one of the most important lasting documents of that individual's school years.

Here are some tips for creating a winning video resume:

1. **Start early.** A person may especially like—and be successful at—a particular job training site at the age of 14, and then may never have the opportunity to do that specific job again. Many years later, it may be difficult (or impossible) to re-create the experience for the purposes of video taping. Recreations are rarely successful because the person may have forgotten how to do the job or the tasks associated with the job may have changed over time. It is possible that a particular person's favorite job was also one of their first, and if the video tape isn't started until the last 1–2 years of the student's schooling, the opportunity to document the success and preference would be lost.
2. **Document all experiences.** Early work experiences may include jobs around the school such as delivering attendance reports, cleaning the lunch yard, or stocking vending machines. These jobs may be done independently, with a job coach, or as part of a work crew. You never know what jobs might be available in the future, or what prospective employers might be looking for. The goal is to document on tape jobs or parts of jobs that showcase the individual's strengths and skills. These strengths may be in the specific tasks related to the job, or they may be in other key domains such as communication, social, and orientation and mobility skills.
3. **Highlight independence and interdependence.** If the individual is successful working independently, document and highlight this. There is nothing wrong, however, with using supports at a job site and showing successful use of these supports. Many persons who are deaf-blind make lifetime use of support service providers on the job, and knowing how to use supports effectively is an important and valuable skill.

Fact sheets from California Deaf-Blind Services are to be used by both families and professionals serving individuals with dual sensory impairments. The information applies to students 0–22 years of age. The purpose of the fact sheet is to give general information on a specific topic. More specific information for an individual student can be provided through individualized technical assistance available from CDBS. The fact sheet is a starting point for further information.

4. **Voice the date and other significant information as you record.** Some time in the future, you may have the time and expertise to lay a voice track over visual footage and make the video resume extra professional in appearance. Just in case that day never comes, however, include basic information as you record, such as the location of the work experience, a description of the task if it isn't entirely clear, and a description of how the task positively supports the mission of the company or work environment.
5. **Keep the video tape in a safe place.** This may sound obvious, but think about how many times this tape will be recorded on or edited *and* over a time span of as many as 7–8 years. In this amount of time there could be many transitions, both at school and home.
6. **Mark the tape with its contents.** Again, as obvious as it sounds, sometimes video tapes *do* get recorded over accidentally. If there isn't a backup copy of the footage, many years of hard work could be lost, and many successful experiences forgotten or overlooked.

* * *

Hoja de Datos

Como Crear un Video Currículum Exitoso

por Maurice Belote, Coordinador de Proyectos, CDBS

Muchos individuos que son sordo-ciegos y/o tienen discapacidades severas son más capaces de lo que pueden aparentar en papel (i.e., reportes escritos, evaluaciones, listas de cotejo, etc.). Cuando se busca experiencias de trabajo, ya sean—voluntarias, “shadowing“, de entrenamiento o pagadas—alguna gente que no está familiarizada con discapacidades pudieran enfocarse más en sus limitaciones que en sus habilidades. Un currículum video-grabado es una manera de demostrar a los posibles empleadores/patronos que esta persona con discapacidades tiene destrezas específicas y habilidades que pudieran ser apropiadas para un trabajo específico. No solo son los empleadores/patronos los que pueden usar este video; el video podría ser útil cuando se esté generando el apoyo de un administrador escéptico, entrenador de trabajo, o maestro. Aunque es una buena idea empezar temprano en la carrera educativa de un individuo, nunca es demasiado tarde para crear un currículum para apoyar la transición de esa persona de la escuela al trabajo. Usted estaría creando uno de los más importantes y duraderos documentos de los años escolares de ese individuo.

1. **Empezar temprano.** Una persona le gustaría especialmente—ser exitoso en—un entrenamiento de trabajo específico a la edad de 14 años, y puede ser que no tenga de nuevo la oportunidad de hacer ese trabajo. Muchos años después, puede que sea difícil (o imposible) recrear la experiencia para propósito de la grabación del video. Recreaciones raramente son exitosas. Porque la persona puede ser que haya olvidado como hacer el trabajo o las tareas asociadas con ese trabajo pueden haber cambiado con el tiempo. Es posible que el trabajo favorito de una persona en particular haya sido también alguno de los primeros, y si la grabación del video no se empiezan hasta los últimos 1 o 2 años de la escuela del alumno, la oportunidad de documentar el éxito o preferencia se habrá perdido.
2. **Documentar todas las experiencias.** Experiencias tempranas de trabajo pueden incluir trabajo alrededor de la escuela, tales como repartir reportes de asistencia, limpiar el area de almuerzo, resuplir máquinas de venta, estos trabajos pueden ser hechos independientemente, con un entrenador de trabajo, o parte de un equipo de trabajo. Usted nunca sabe cuales trabajos podrían estar disponibles en el futuro, o que pueden estar buscando los posibles empleadores. La meta es documentar en video trabajos o partes de trabajos que muestren las fortalezas del individuo o las destrezas. Estas fortalezas pueden ser tareas específicas relacionadas con el trabajo, o pueden ser en otras áreas claves tales como comunicación, socialización y destrezas en orientación y movilidad.

Las hojas de datos de Servicios Para Sordos-Ciegos de California son para ser usadas por ambos familias y profesionales que ayudan a individuos que tienen dos sentidos incapacitados. La información aplica a estudiantes 0–22 años de edad. El propósito de la hoja de datos es para dar información general sobre un tema específico. La información más específica para un estudiante individual puede proveerse mediante la asistencia técnica individualizada disponible desde CDBS. La hoja de datos es un punto para comenzar una información adicional.

3. **Resalte independencia e interdependencia.** Si el individuo puede exitosamente trabajar independientemente, documente y resalte ésto. No hay nada malo, en todo caso, el usar apoyos en un lugar de trabajo y mostrar éxito usando esos apoyos. Muchas personas que son sordo-ciegas hacen uso toda la vida de servicios de apoyo en el trabajo, y el saber como usar esos apoyos efectivamente es una destreza importante y valiosa.
4. **Diga la fecha y otra información importante mientras usted graba.** Alguna vez en el futuro, usted tendrá el tiempo y el conocimiento para agregar una pista de comentarios al pietaje visual colleccionado y darle a un video-currículum un aspecto más profesional. Por si acaso este día nunca llega incluya información básica en su grabación, tal como el lugar de la experiencia de trabajo, la descripción de la tarea si no está enteramente clara y una descripción de como la tarea apoya positivamente la misión de la compañía o el ambiente de trabajo.
5. **Mantenga el video cassette en un lugar seguro.** Esto puede sonar obvio pero piense cuantas veces éste video- cassette será grabado o editado en el transcurso de 7 a 8 años. En éste tiempo puede que haya habido muchas transiciones tanto de la escuela como en el hogar.
6. **Marque en el cassette el contenido del mismo.** De nuevo tan obvio como suena algunas veces los video-cassettes son regrabados accidentalmente. Si no hay una copia de reserva de el pietaje, muchos años de trabajo arduo, podrían ser perdidos, o muchas experiencias exitosas olvidadas o pasadas por alto.

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