



reSources

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Perspectives on the Transition to Adulthood: An Interview with Cathy Kirscher, Regional Representative with Helen Keller National Center

What does Helen Keller National Center (HKNC) do and what is your role at the agency?

The HKNC mission statement sums up our goal as an agency: HKNC's mission is to enable each person who is deaf-blind to live and work in their community of choice.

HKNC was authorized by an act of Congress in 1967 and is a national rehabilitation program serving youth and adults who are deaf-blind. HKNC has a training center in Sands Point, New York (located on Long Island), as well as field services in each of the 50 states. HKNC accepts approximately 36 students at a time at our Center in New York who are deaf-blind from age 16 and above. Most students who attend the Center have a vocational goal



and all have a desire to become as independent as possible. Younger consumers may be exploring life after high school, continuing their education or looking at work options.

The PATH program at HKNC offers evaluation and training to consumers who are deaf-blind with developmental disabilities. HKNC utilizes a Personal Futures Plan (PFP) to develop and reflect the individual needs, preferences, ability, and interests at the work, home, and community for the students in this specialized program. For more information about the services of HKNC NY, visit the website at www.hknc.org.

My job title is HKNC Regional Representative. I provide consultation, training, information and advocacy to consumers, families and agencies in the southwest region including Arizona, California, Hawaii, Nevada, Guam and American Samoa. HKNC has 11 regional representatives located in 10 offices across the country.

What kind of services can you provide? What can't you provide?

Regional representatives for HKNC help link deaf-blind individuals, families, and agencies with appropriate resources and provide in-service training to those resources as necessary. Generally, I would say that

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Regional Representatives for HKNC do not provide direct services, yet all my work feels very personal and like a direct connection with individuals and families in this region. As an example, if a person needs to learn to use a white cane, we do not provide that kind of direct O&M training in the field but we do try to connect people to appropriate resources in their home communities so they can learn specific skills as needed.

Can you, or do you, make recommendations for people who can do assessments?

This is a tricky question because as the Regional Representative I can come in to do an initial “assessment” of the situation and look at the needs of an individual and their family and help develop a plan with recommendations. Formal assessments in specific areas like psychological, educational, orientation & mobility, etc. are referred on to the appropriate resource in each field.

Unfortunately, as most of us know by now, there are a limited number of service providers who have experience providing comprehensive assessments for individuals who are deaf-blind. It can be complicated—but not impossible—to find the right match.

How do you work with Regional Centers in California?

California has 21 Regional Centers with more than 40 offices located throughout the state that serve individuals with developmental disabilities including individuals who are deaf-blind. I have been called in as an advocate and resource with adults especially during IPP meetings as part of the “team” working with people who are deaf-blind. HKNC has a National Training Team that has also provided training with me at five of the Regional Centers in California.

How does Rehab really work? And what can people do to make connections with Rehab?

Department of Rehabilitation (DOR) bills itself as assisting people with disabilities “to obtain and retain employment”, and maximize their ability to live independently in their community. Back when I first started at HKNC, I remember advocating for consumers and their families to open cases with DOR by age 14. This age was looked at as the magic number for a person who was beginning the transition process. Realistically, I still encourage all families to consider opening a case with DOR, but I tell them it might be more appropriate to wait

until it is within approximately two years of the student’s projected high school completion.

We do not have deaf-blind specialists in our state under DOR, but we do have rehabilitation counselors for the deaf (RCDs) and rehabilitation counselors for the blind (RCBs). I interact often with DOR counselors because this agency is often the main funding source for training and technology whether a student has a goal for competitive employment or supported work. DOR counselors can work in tandem with Regional Center staff in assessing the potential for supported work for individuals who are deaf-blind with developmental disabilities.

How can people find Support Service Providers?

We do not have a formal Support Service Provider (SSP) program in California at this time. We do however, have three consumer organizations in California: the Northern California Association of Deaf-Blind (NCADB), the Southern California Association of Deaf-Blind (SCADB), and a consumer group in Fresno. Each of these consumer organizations keeps a running list of volunteers and SSPs, especially for their monthly meetings. It may help people to check in and connect with one of these consumer groups to find potential SSPs in their areas.

Only 13 states have formal SSP programs. The American Association of the Deaf-Blind (AADB) has developed an SSP Pilot Project with the Deaf-Blind Service Center (DBSC) in Seattle and HKNC as supporting partners. Two pilot sites have been identified in Washington, D.C. and Texas, and an expansion of DBSC is planned to include eastern Washington State. The Project is currently seeking federal funding for these pilot sites. After the pilot period, Congress could potentially fund SSP services in other regions of the country. The goal is to establish a national network of professionally trained, skilled SSPs.

How do Medicaid waivers in California work? Is it something an individual can get, or is it just a huge amount of funds that is pooled at the state level to pay for services through DDS?

Texas is the only state that has a Medicaid waiver program specific to deaf-blindness. This program has really put Texas on the map as being in the forefront of providing adult services for individuals who are deaf-blind and who also have developmental disabilities. It would be great to

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petition California and establish a similar program here that provides supports for housing and employment.

What are the different alternatives for services in adult life?

There are as many options for adult services as there are different people who experience deaf-blindness—from employment to housing to recreational outlets. It's great that we have some trailblazers among us who have helped shape global services and supports for individuals with disabilities. If we can continue to look at each person's situation and needs as unique, we can continue to create personal options for services that will be a better fit for this very diverse group.

What advice do you have for students who are nearing transition age?

One technique we use at HKNC New York is a person-centered planning process, which begins with the focus on the deaf-blind individual and looks at both the formal and informal community supports that a person might have in his or her life. Personal Futures Planning (PFP) is another very similar tool used by teams supporting individuals with disabilities to plan and develop future visions. We obviously do have some structured programs in adult services, but I don't think any of the programs take into account the whole of an individual. Developing a person-centered plan or personal futures plan helps the person and everyone involved look at the bigger picture and I think it is a helpful tool.

What is special about this specific age group?

I think it is important for all of us to remember that students who are deaf-blind in this transition age group have the same hopes and dreams that we all have for a happy and satisfying life.

I love the parable that was written by Michael McCarthy several years back that began with,

“In the beginning there was placement... a person arose who was a client, but who was also a prophet, and said:

*I don't want to be a client,
I want to be a person.
I don't want a label,
I want a name.
I don't want services,
I want support and help.
I don't want a residential placement,
I want a home.
I don't want a day program,
I want to do meaningful and productive things.
I don't want to be "programmed" all my life;
I want to learn to do things I like, and go places,
which I like.
I want to have fun, to enjoy life and have friends.
I want the same opportunities as all of you:
I want to be happy."*

I think our task as service providers is to help make sure all people we work with have a name, supported help if they need it, a place to call home, meaningful activities in their lives—with fun places to go and true connections with friends and family—in their quest to live well. Do we have all of these options available to every person in adult life? No, but we're working on it!



Fanmanflavah's Life is Good: An Interview with Jarrett Heartsmann and his Mom on Living on his Own

Jarrett Heartsmann is a young man who has completed his school program and transitioned into a good adult life in Sacramento. Jarrett is in supported living with his own staff and renting part of a home in a lovely, tree-filled neighborhood in the capital city. Jarrett's staff is employed by an agency called Creative Living Options and his mother, Sandra Suitor, is a great resource for his staff. Jarrett has CHARGE syndrome and has limited vision and hearing as well as some physical challenges. In addition to his busy life, Jarrett finds time to serve on the CDBS Advisory Committee. CDBS recently interviewed Jarrett (JH) and his mother Sandra (SS), and found out some interesting things about his life.



SS: On a daily basis, he helps with breakfast, chooses his own clothes, and does usual daily chores. He has different schedules for the afternoons during the week. On the weekends, Jarrett goes to festivals and often he plays with groups at different dances and festivals. He goes to concerts and on Sundays he is a part of the gospel band at his Church—Faith Fellowship Community Church.

CDBS: What are your dreams for the future?

JH: I would like to have a new keyboard!

SS: This is important to Jarrett as music is a great love and he has great talent. He is always looking for a new keyboard and has many.

JH: I would like to have two fans in one room.

SS: Jarrett is very interested in ceiling fans. If you get to meet him, he might very well ask if you have any ceiling fans in your house and how many blades they have.

JH: I would like to own my own home.

SS: Jarrett is presently renting a home that is owned by the family of a young man who is also in supported living.

CDBS: Who are the people who support you in your life and how do they support you?

JH: Sharisa, Renee, Jamie, Bobbie and Deborah. Staff helps me go to Old Sacramento—a fun place. Staff helps me pay my bills from the bank and helps me with grocery shopping. My mom takes me dancing with her.

SS: These staff members are hired and trained by Creative Living Options. Johnnie is the Community Service Facilitator and she oversees the house and the staff. The staff helps with daily living skills in his life. Staff is with Jarrett 24/7.

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CDBS: Where do you live?

JH: Sacramento, California.

SS: Jarrett has lived most of his life in Sacramento. Jarrett is a part of his community and especially his church community. Jarrett lived at home with me until 2002, almost 6 years ago. Now he rents his own house and he is making his own decisions about how to live.

CDBS: What is your daily life/schedule like?

JH: Chores on Tuesdays, school in the afternoons, choir rehearsal in the evening, Karaoke on “Disco Saturday Nights” at Zigatos.

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CDBS: What is one thing that school did that helped to prepare you for life as an adult?

JH: I took music and it affected me in school by playing piano.

SS: Jarrett took band and jazz band during high school and his transition years and he did really well. Playing the keyboard is a big part of his life and who he is. At community college, Jarrett takes weight training and aerobics and he says it helps him maintain his body. Jarrett has scoliosis and this body training helps him with his general well being and breathing. The community college staff also continues to help Jarrett with his music training. Jarrett has a great social life. He goes to a lot of parties and when he is out in



the community people recognize him. Recently he went to a jazz concert at a local hotel and one of the musicians in the group saw him and recognized him from high school.

Jarrett's life in Sacramento is definitely a great example of building community through the years and how this can work to make life good!



Save the Date ~ December 8!

COPE-DB

HOLIDAY

PARTY



Los Angeles area

Creating Community for Adult Life: Planning an Effective and Exciting Transition

by Nancy Cornelius and Jackie Kenley, CDBS Family Specialists

[This article is based on a presentation by the authors at the 8th International CHARGE syndrome Conference, July 26-29, 2007 in Costa Mesa, California.]

What is transition, anyway?

We all experience many transitions throughout our lives. This article explores the process of transition for young adults with disabilities and special needs, from school to adult life. According to the Individuals with Disabilities Education Improvement Act (IDEA), the term “transition services” means a coordinated set of activities for a child with a disability that—

- ❖ is designed to be within a results-oriented process, that is focused on improving the academic and functional achievement of the child with a disability to facilitate the child’s movement from school to post- school activities, including post-secondary education, vocational education, integrated employment (including supported employment), continuing and adult education, adult services, independent living, or community participation;
- ❖ is based on the individual child’s needs, taking into account the child’s strengths, preferences, and interests; and
- ❖ includes instruction, related services, community experiences, the development of employment and other post-school adult living objectives, and, when appropriate, acquisition of daily living skills and functional vocational evaluation.

[For more information about IDEA, go to <http://idea.ed.gov> and search on the word “transition” in the Part B section.]

Looking into the future can be difficult and requires self-reflection, self-assessment, focus, creativity, and flexibility. Trying to visualize a perfect future for your child may seem like looking for “the land of Oz”. Perhaps your vision is a little blurry, perhaps Oz looks differently than you

expected. Maybe it really looks more like Kansas. Even though it may be a little scary, it is essential to project into the future to create an effective transition plan for your son or daughter as he or she prepares to leave school and enter the world of adult life and adult services.

Planning for the future

There are a variety of person-centered tools available to assist families in the futures planning process (i.e., to identify desired outcomes and develop strategies that ensure success). Here is one tool just to get you started:

It’s Never Too Early; It’s Never Too Late!

www.mncdd.org/extra/publications.htm

It is never too early to begin compiling documentation that captures your child’s skills and abilities, likes and dislikes, communication and other support needs, and possible support providers. Video resumes can be effective tools for documentation. (See Resources for planning at the end of this article.)

Strategies for planning an effective transition from school to adult life

KNOW the Individuals with Disabilities Education Improvement Act. It is the federal law that mandates appropriate transition services and it drives local programs.

RESEARCH local programs and get to know your community options. Service delivery models vary greatly from state to state and from community to community within states.

KNOW definitions and terms used by local service agencies. Definitions are not necessarily consistent nationally, regionally, or locally. Clear communication is essential!

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Know the members of your child's team and use them

Every child receiving special education services has an educational team that consists of the student, family members, special education teacher, general education teacher, administrator, and other specialists. The transition planning team may include the educational team, but it also includes other people who know and love the child/focus-person.

The planning team may include:

- ❖ Focus person
- ❖ Family members
- ❖ Friends
- ❖ Educational team with related services staff (therapists)
- ❖ Adult service provider agency representatives
- ❖ Welcoming agency representatives

Through the planning process the team will identify individual support needs of the focus-person and possible support providers:

- ❖ Interpreter
- ❖ Intervener
- ❖ Communication specialist
- ❖ Vision & hearing specialists
- ❖ Personal attendant
- ❖ Job coach/developer
- ❖ Behavior specialist
- ❖ Medical specialist
- ❖ Orientation & mobility specialist

Through the planning process the team will also identify possible adult service agencies/providers:

- ❖ Habilitation/rehabilitation
- ❖ Local day programs
- ❖ The ARC
- ❖ Regional Center (CA)
- ❖ Transportation services
- ❖ Services for the blind
- ❖ Services for the deaf
- ❖ Helen Keller National Center
- ❖ Mental health services

How the futures plan relates to the student's Individual Education Plan and Individual Transition Plan

The futures plan identifies:

- ❖ Hopes and dreams of the focus-person
- ❖ Likes and dislikes
- ❖ Strengths upon which to build
- ❖ Weaknesses to be strengthened
- ❖ Personal and community links
- ❖ Healthcare, communication, and behavioral support needs

The preferences identified by the futures planning process are the basis for the goals and objectives on the Individual Education Plan/Individual Transition Plan.

Comprehensive transition plans consider all possible community services and options and customize an array of appropriate services to meet the needs of the focus-person. Community services and options to be considered include but are not limited to:

Educational options

- ❖ College/university
- ❖ Community college
- ❖ Regional occupation programs
- ❖ Other training options

Vocational options

- ❖ Paid employment
- ❖ Volunteer work
- ❖ Supported work

Living options

- ❖ Home with family
- ❖ On own with or without roommates
- ❖ Supported living with or without roommates
- ❖ Group home

Recreation/leisure options

- ❖ Swimming
- ❖ Outdoor recreation
- ❖ Dancing

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- ❖ Drumming
- ❖ Music
- ❖ Yoga & exercise classes
- ❖ Sports

Needs/wants to be considered

- ❖ Transportation
- ❖ Supervision
- ❖ Friends
- ❖ Activities/events
- ❖ Communication

Getting from the plan to the reality

Learn how to make lemons into lemonade. There are many obstacles and barriers on the path to adult life. Try to see each one as an opportunity.

Listen. Every team member has valuable ideas and input. Listen carefully.

Identify local resources. Resources and services are unique to each community. Knowing your local resources is critical to successful community living.

Get on waiting lists, if necessary. Do not wait until your child leaves school to apply for enrollment in adult programs and services. There are often long waiting lists for quality services and programs.

Identify funding sources (SSI/SSA). Funding streams and mechanisms are different from state to state. Identify appropriate funding for your child’s needs. Apply early for the funds. Stay in contact with funding agency representatives.

Making it happen

Building a future takes teamwork, commitment, and community. Futures planning weaves together components from many community agencies, services, and systems. No one can do it alone. So if you start to feel overwhelmed or confused, ask for help. Remember, even though your child is reaching adulthood, it still takes a village!



Resources for planning

Texas School for the Blind, *Transition from School to Adult Life in the Community*, a two-part planning sheet: www.tsbvi.edu

It’s Never Too Early It’s Never Too Late! www.mncdd.org/extra/publications.htm

A Good Life. www.plan.ca
(search for the book A Good Life)

How to Create a Winning Video Resume. www.sfsu.edu/~cadbs/27VideoResume.pdf

Suggestions for Creating Successful Transitions from School to Adulthood. www.sfsu.edu/~cadbs/35Transition.pdf

Transition to Adult Living and Information and Resource Guide. www.calstat.org/info.html

D-B LINK. www.nationaldb.org/ISDefault.php
(search on transition)



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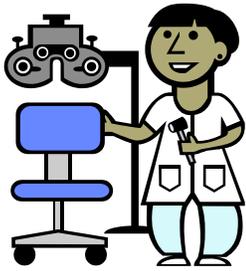


University-CDBS
Partnership Project

As California Deaf-Blind Services enters its final year of the current 5-year funding cycle, we wish to thank our dedicated *Advisory Committee members* for their sage advice, thoughtfulness, and wisdom. They are candid, honest, and firmly committed to the children and youth served by the project, their families and educational teams. CDBS is a much better project because of their input. *Thank you, Advisory Committee!*

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Save the Date!



12th Annual Lowenfeld-Akeson Early Years Symposium

“Communication: It’s the Foundation”

*Strategies for Teaching Young Children
who are Deafblind or Multiply Impaired*

Saturday, February 2, 2008

8:30 am – 3:00 pm

California School for the Blind, Fremont

Featured Presenters:

Deborah Chen, PhD

Professor, Special Education
Cal State University Northridge

Robbie Blaha

Outreach, Texas Deafblind Project

Lunch Meeting – CAPVI General Meeting and Advocacy Presentation - all welcome

Afternoon Panel – A group of parents and consumers will share their experiences

Show and Tell – We invite you to bring along and share materials that are used with students to enhance communication (communication boards, Intellitools, etc)

--Registration info will follow--

For info, contact Michael McFarland, Blind Babies Foundation
(510) 446-2229 or mcfarlandmike@blindbabies.org

***~Parent/Family Scholarships available due to the generosity of the
William Silverman, M.D. Scholarship Fund~***

Symposium Co-Sponsors:

Blind Babies Foundation (BBF)

California Association for Parents of Children with Visual Impairments (CAPVI)

California School for the Blind (CSB)

Northern California Association for the Education and
Rehabilitation of the Blind and Visually Impaired (NCAER)



reSources

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