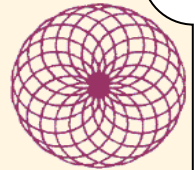


North Bay Regional Center Press



J U N E 2 0 1 1 W W W . N B R C . N E T

SPOTLIGHT ON INDEPENDENCE: CHOOSING TO EAT & GROW

In This Edition

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- **Responding to Budget Cuts**
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The Sabatino family welcomed their healthy new boy, Jasper, home. Jasper was a bright and curious baby who slept well and was developing just like his older sister. Melissa, his mother, was sure he would thrive in his new home. At his first check-up, his doctor confirmed that Jasper was, indeed, a healthy baby and was meeting all his developmental milestones. He hadn't gained much weight, though, which concerned Melissa, but she was assured it was nothing to be concerned about. She figured he was just "a spitter," like many babies, when it came to his eating skills.

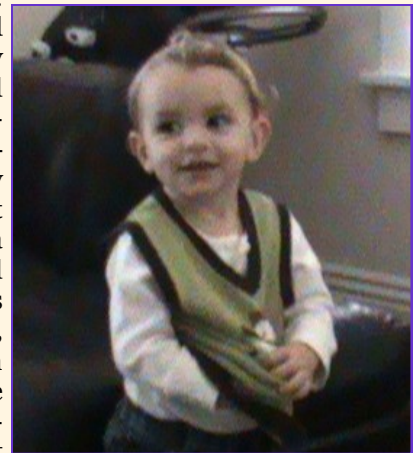
As the days progressed, though, Melissa became increasingly worried: "At first I thought he just spit up a lot, but he didn't keep *anything* down!" What had begun as a small worry about Jasper's eating habits was turning into a serious concern. As the months went by, Jasper's lack of weight gain became an eventual decline in weight. This weight loss- when he should have been gaining weight- coupled with his inability to keep food down was both alarming and unhealthy. Melissa reflected on this difficult time, trying everything she could think of to get him to keep his food down, only to be met by an increasingly resistive baby. "He was afraid of food!" she says.

Despite consultations with doctors and various specialists, nothing was helping Jasper keep his food down and no one seemed to understand what was wrong. At almost 14 months, Jasper's parents were exasperated: something was seriously wrong and no one seemed to know what to do to help! That was when they were tipped off to try an occupational therapist, and Ila, an OTR specializing in feeding issues, was contacted.

After hearing about Jasper, Ila suspected he had GERD (Gastro-Esophageal Reflux Disease), and recommended Melissa give North Bay Regional Center a call for Early Intervention Services as he was clearly at risk for a developmental delay. Early Intervention Specialist Angelica Smith began working with the Sabatino family and assessed Jasper's need for services, coordinating with Ila to begin work without another moment's delay. After Jasper's doctor prescribed a medication to address the GERD, Jasper's appetite was restored. But because for 14 months he had been gagging on his food, he also needed to *learn how* to eat and to overcome his fear of eating that had developed as a result of his having pain and discomfort for so long. Ila worked to show him eating was fun and taught Melissa how to help Jasper learn to eat while desensitizing him from his fears. She played games like blowing bubbles and whistles that helped him strengthen the muscles of his mouth that had atrophied from disuse. These muscles needed to be rehabilitated in order for Jasper to eat correctly.

Jasper's rehabilitation was quick and he began gaining weight; and as his teeth came in, he also learned to use them to chew. Melissa adds, "It was so wonderful to have the help of Angelica and Ila- *they* supported me and understood that there was a problem." With Jasper now eating, gaining weight and on track to develop as a typical toddler, Melissa was comfortable with his progress. She notified Angelica that she didn't think there was a need for continued NBRC services, and Jasper 'graduated' from the Early Intervention Program at 18 months, now a typically developing little boy.

Nearly 80% of children ages birth to 3 years old that come into the Early Start program graduate from Early Start and are not diagnosed with a developmental disability at 3 years of age. Jasper is well on his way to leading an independent life and choosing foods that he likes to eat with his family.



Jasper Sabatino pauses before he runs

TRAINING & WORKSHOP UPDATES

Marin Autism Lecture Series Marin County Office of Education 1111 Las Galinas, San Rafael
Students/Parents \$20 per lecture; professionals \$25 12:00-2pm Contact Karen Kaplan 415-497-3751
or karensupportsu@comcast.net; one per month **Sept 13 – May 15, 2012**

Collaborative Autism Training & Supports (CATS) Applications being taken for child and family support: For further information contact: Dr. Lorna Catford, Program Director, Sonoma State University, (707) 664-2402, lorna.catford@sonoma.edu

CATS Support Group for Parents of children with ASD– California Parenting Institute 3650 Standish Ave, Santa Rosa 585– 6108 **1st Thursdays 9-11:00am**

Special Education: What to Know workshop hosted by Matrix @ Becoming Independent, 1425 Corporate Center Pkwy, Santa Rosa: register by calling 415-884-3535 (In **Spanish** Only) **June 9, 11:00am**

Clinical Workshop Series Becoming Independent & Family Resource Agency Santa Rosa
\$15 per session- Contact 524-6677 npadilla@becomingindependent.org; Wednesdays **June 22-Aug 24 5:30pm**

Autism Support Group for Latino parents with ParentsCAN contact Monica at 707-253-7444 x 201
or email monical@parentscan.org **June 15 9:30-11:30am**

Grandparents Raising Grandchildren with ParentsCAN obtain information, resources, and connect with others! Contact Antoinisha, 707-253-7444 x 108 antoinishaw@parentscan.org **June 23 11:00-12:30**

COMMUNITY EVENTS

The Big Luau! Join Becoming Independent and the City of Santa Rosa for the next fun-filled dance at Steele Lane Community Center 415 Steele Lane, Santa Rosa \$5 738-3294 **June 13 7-8:30pm**

Wee Walk: jumpies and booths with information; Come on down and have fun with Early Learning Institute Santa Rosa: Contact Ronnie 328-2006 www.earlylearninginstitute.com **June 4, 2011**

YMCA Adaptive Aquatics 1111 College Ave. Santa Rosa **Saturdays 10:30-12**
Contact Sierra Van Der Kamp 707-799-2253

Napa Parks and Recreation Summer BBQ and Bocce Ball. Contact Napa Parks and Recreation at 257-9529 or www.NapaRec.com **June 18, 11:30-1:30**

Napa Parks and Recreation Social Night, \$3.00 located at 1500 Jefferson St., Napa.
Contact Napa Parks and Recreation at 257-9529 or www.NapaRec.com **June 3, 6:30-8:30pm**

Becoming Independent puts out a weekly Monday Update with current community, news, and family support information. If you'd like to sign up, contact Sybil Halloran: Shalloran@becomingindependent.org

Grass Roots Day Brings NBRC to Capitol

With deep cuts pending, NBRC Board President Martha Cornejo and Board Members Michael Statti, Margi Stern, and Linda Washington joined Bob Hamilton and Pamela Madden-Krall this year for Grass Roots Day at the state capitol. With only a short time in the morning hours before an afternoon budget vote, while meeting with Assemblymember Michael Allen (Napa and portions of Solano and Sonoma Counties) they reminded him that only 40 years ago, people with developmental disabilities were unseen, tucked away in large institutions. As a result of a decade-long struggle, they are here today lobbying for continued support and funding to sustain the Lanterman Act including the rights to make their own choices and self-direction this law protects.

As a former psychiatric nurse at Sonoma County's Crisis Center, Assemblymember Allen is familiar with NBRC and discussed his continued support for the work that is done by regional centers. Assemblymember Allen agreed with Bob Hamilton that cuts should not target the most vulnerable populations and gave his support. With a background that includes setting up the Sonoma County Day Care Center, Michael Allen understood the impact cuts will have on families with children, and how ripple effect can cause greater economic instability at all levels



Michael Statti tells Assemblymember Michael Allen about impact cuts will have on him.



Assemblymember Allen discusses budget with Linda Washington and Bob Hamilton.

With the afternoon vote keeping legislators on 'the floor,' meetings with staff for Senator Wolk and Assemblymember Mariko Yamada proved again that support for people with developmental disabilities is in place for our North Bay catchment area. With the Association of Regional Center Agencies (ARCA) keeping a close eye on budget developments, legislators who may not understand the impact of cuts have been targeted to get the support needed. As Michael Statti put it, "We need supports to live and work," and everyone should be able to . . .

Next on the Chopping Block: Medicaid

The House of Representatives recently passed a fiscal year 2012 Budget Resolution that would **cut Medicaid by 20%** (or about \$770 billion over 10 years) and then cap it and block grant it to the states with annual growth at less than the rising health care costs. What does this mean? With nearly \$1 billion each year coming to the regional center system through Medicaid reimbursements to services such as respite, assistance with living in the community, hospital care and prescription drugs, a cut of this size could create waiting lists for services and shift costs to individuals and families. Block grants are fixed amounts of money that would force states to prioritize spending amongst competing groups, e.g., elderly, children, and people with developmental disabilities. Contact your state representatives and Senators and [Click Here](#) for more information.

Executive Corner: Bob Hamilton**Cuts Require Doing More with Less**

As this issue of the NBRC Press goes to press, we are in the process of legislative review and approval of the Governor's May Revision of the budget for the coming fiscal year, which begins on July 1st. There have been budget committee hearings in the last few days and there will be policy committee hearings as well for the next couple of weeks. In many cases, these hearings are broadcast on the internet at www.calchannel.com and I encourage you to watch and be motivated to contribute your testimony in this process.

These hearings are helpful in learning about details of the proposals to achieve \$174 million in general fund savings as well as hearing the public testimony regarding these proposals from the various participants in the service system. There are a number of proposals that range from changes in programs to parental fees to unallocated cuts to operations. The Department of Developmental Services (DDS) has labored to keep these budget cuts as far away from the person receiving services as possible. The Association of Regional Center Agencies (ARCA) has reviewed these proposals and supports most of these proposals with the exception of parental fees, use of paraprofessionals to provide behavioral services, the transfer of the prevention program to the family resource centers and the unallocated cut to operations. You can examine the many details and nuances of the DDS proposals and the ARCA positions at their respective websites at www.dds.ca.gov and www.arcnet.org respectively.

In addition to these proposals we are already under the control of a budget trailer bill that was passed into law in March, even though there was no budget bill passed at that time. There are a number of "efficiency" and "transparency and accountability" provisions that have projected savings (otherwise known as cuts) that were part of a \$750 million cut package in Governor's budget that was proposed in January. The Legislature then reviewed these proposals and reduced the cuts to \$533 million, of which the \$174 million are a part. The remaining cuts are embodied in the continuation of the 4.25% reductions in vendor rates and regional center operations and, as previously mentioned, the "efficiency" and "transparency and accountability" measures.

I am not including a great deal of detail here and refer the reader to the previously mentioned websites of DDS and ARCA for further analysis. My focus here in this article, is that these are extremely difficult times for our service system that we must all work together to find ways to endure these cuts and preserve this precious service system while simultaneously advocating for our people. We recognize that providers will have to find creative ways to continue their programs as they are now operating with less funding coming in; that families will need to find other support systems to meet their needs with these new changes; and, that the regional center will have to find better methods to provide services in the face of increased requirements paired with unallocated cuts. We are all going to have to find ways to do more with less. In the process of finding these new ways, let's not lose sight that it takes all of us working together to achieve these goals and survive this economic downturn while we hope for brighter days.

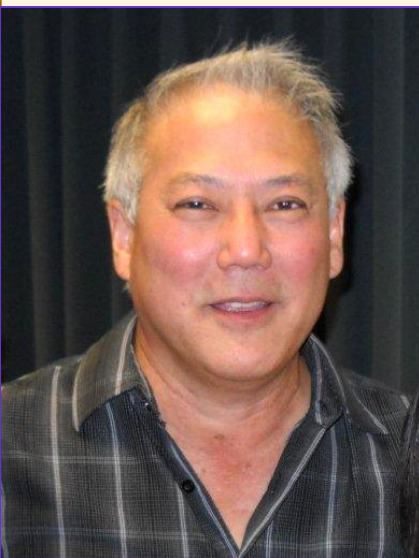
A Bittersweet Farewell

By Kelly Weber

North Bay Regional Center said goodbye to one of its most dedicated employees, David Katayama, Children’s Services Manager, as he retired May 1st after thirty-two years of service. David’s interest in the field of developmental disabilities began when he was in high school. He was a member of a volunteer group that visited with residents at what was then Sonoma State Hospital, now Sonoma Developmental Center. As a volunteer, he wrote letters for the residents and went with them on walks.

David started working at NBRC in 1978 as an Assessment Counselor. He was promoted to various positions throughout the agency, including Senior CPC, Case Management Supervisor, Program Director, and Coordinator of County Services, eventually taking his final position in 1998 as Children’s Services Manager. As the Children’s Services Manager, he was responsible for overseeing Early Intervention Services, Children’s Services, and at one time Intake and Assessment. David was a compassionate advocate for children with special needs and a compassionate leader. Nona Koroluk, Early Intervention Supervisor, said “David was a great role model: caring, supportive, a clear communicator, responsive, and always looked for and inspired the best in me.” When asked about his experience at NBRC, David said: “The staff, the community of clients, their families, and the vendors have been my inspiration over the 32 plus years. I learned a lot from them up until I retired, and I hope that what I gave back was equal to the task of what was given to me. I feel very fortunate to have been able to combine my educational accomplishments with my passions for working with such a special population of people. I am extremely grateful for the opportunities that I have had and for crossing paths with so many incredible people.”

As he retires, David is taking with him years of knowledge and experience, as well as great leadership. He will be dearly missed by his colleagues at NBRC and members of the community. We wish him well in his retirement!



NBRC staff and community celebrate David's achievements



Many Speak Out - Opposing Cuts

In what may be one of the most important civil rights movements of our times, the current fiscal crisis in California and imminent cuts to services has ignited a storm of responses at every social-level.

In March Senator Mark DeSaulnier, D-Concord, submitted a Guest Commentary to Contra Costa Times reflecting on the legacy of Frank Lanterman and the current political climate where “many believe that doing the right thing for the right reason is antithetical to politics” ([Click here](#) for complete story).

If bridging the budget gap requires bridging the political gap, a dose of shock therapy may be in order. Parent Laura Repke postulated her son may be better off on death row ([SF Chronicle Op Ed](#)). She notes the steady decline in services- “Rob lost his dental coverage, his physical therapy and his vision care - despite his difficulty walking and seeing. Now the state sees room for another half billion dollars in cuts. That's why Death Row - with its steady funding and a decade of room and board - is looking better and better. (San Quentin State Prison even offers

views of San Francisco Bay and is set to receive a new \$356 million facility.)”

Challenges and hard choices are being weighed at every level. It can be dizzying to keep up with daily updates, and fears grow with a sense of impending doom as the budget deadline grows near. With the recent release of recommendations to find another \$174 million in cuts to services, Public Forums in Oakland, Sacramento, and Los Angeles brought more voices to the table. Attending from NBRC, Executive Director Bob Hamilton and Director of Client Services

Alfonso Carmona waited for hours in what became a maze of security checks to enter the Oakland Federal Building, consumers and families both disappointed by the access issues. But once in, a well organized dialogue was created with participants' highlighting the real-life impact of cuts: service agencies shutting down, personal care and attendant needs unmet, lack of access to medical and dental services that could result in life-threatening situations. “The safety risks alone these cuts create could cost us more in the long run,” notes Alfonso Carmona. If ever there was a time for teamwork and collaboration, this next year will test our system's abilities. [Click here](#) to see the final proposals and legislation

“Many believe that doing the right thing for the right reason is antithetical to good politics”

-Senator Mark DeSaulnier, D-Concord



Client Program Coordinators Rise to Daily Challenges

Adult Supervisor Joanne Giardello reflected on the interviewees question: “What does a typical day look like?” For Client Program Coordinators (CPCs), a “typical day” involves any number of surprises requiring advocacy, crisis intervention, and/or court reporting in the service coordination and monitoring for up to 80 individuals per caseload. With documentation and/or reporting required of all case management activities, CPCs often find themselves balancing multiple needs simultaneously. “While you are doing crisis intervention, you're juggling multiple hats,” says adult services CPC Anna Hiser, “as an advocate, a liaison, an NBRC representative, a mandated reporter, and a trusted support for the consumer and family.” Trust is at the core of all case management services, confidentiality being paramount to interfacing with the many public agencies CPCs must collaborate with in the course of case management: schools, Child Protective Services, Adult Protective Services, hospitals, bio-ethics committees, courts, attorneys and probation officers, police and prison guards, and Sexual Assault Response Teams to name a few. “It's a huge responsibility when we are looked upon to make someone's voice be heard,” Anna adds. For CPC Daniel Morris, that responsibility was recently tested when a hospital surgeon questioned doing open heart surgery, speculating on the consumer's ‘quality of life.’ Capable of signing her own consent, with NBRC's team of a clinician, a clients rights advocate, Daniel and his supervisor advocating on her behalf, the surgeon was convinced to perform the surgery and she continues to thrive in her community.

Skilled at answering questions, facilitating meetings, building trust and confidence, advocating, and understanding the legal ramifications of the Lanterman Act in protecting consumer rights are all core to case management. With staggering statistics of up to 80% of people with development disabilities being sexually abused, a call from the police, the hospital, or a desperate parent or consumer is not unusual. But through the work of NBRC's staff and continued community outreach, public education and awareness may some day make a “typical day” more routine for CPCs. Until then, CPC's respond to the extraordinary demands of case management work.

V E N D O R S A C K N O W L E D G E N B R C

The rewards of case management and service coordination are constantly revisited in the triumphs people with developmental disabilities celebrate, and recognition for the work we do by our vendor community reminds us that it does, indeed, take a village. NBRC is proud of the great work that is accomplished through our interdisciplinary teams and this year three Client Program Coordinators (CPC) and one supervisor from our Santa Rosa office were all recognized for their outstanding work.

Becoming Independent’s Community Services Director, Lauren Meiklejohn, recognized CPC Kathy Fitzjarrell and Supervisor Deanna Heibel for Outstanding Service to People with Disabilities. “Kathy has a long relationship with BI and is the CPC for many CLS participants. We appreciate her kind and professional manner, her follow through (you can count on her!) and last but not least she is very knowledgeable about the system and is full of resources,” says Lauren and adds, “Deanna has been a ‘voice of reason’ and she has consistently listened and thoughtfully weighed our concerns in regard to participant issues.” At CHDC’s Redwood Empire Industries, CPC’s Michael Loya and Rich Depp were given the Community Recognition Award. Says Eileen Allen, Employment Services Coordinator, “they were picked for how well they coordinate services for consumers and for their work with counselors here.” NBRC congratulates Kathy, Deanna, Michael and Rich on their well-deserved recognition for excellent work.

S E C O N D A N N U A L A U T I S M S Y M P O S I U M

With keynotes speakers Dr. Barbara Firestone and Dr. Lou Vismara kicking off the 2nd Annual Sonoma County Autism Symposium, over 150 families and professionals were treated to inspirational stories. Hosted by Anova Education Center and sponsored by the Autism Community Team (ACT) with host Dr. Patrick Maher, 14 community agencies brought information and networking opportunities to attendees.

Dr. Vismara, co-founder of the MIND institute, emphasized the importance of speaking in “one voice” where it comes to lobbying for legis-

lative action, and urged for the passage of SB 166 (Steinberg) requiring health insurance coverage for treatments for individuals diagnosed with ASD. Dr. Vismara concluded with his “3Bs for Change: Be Involved. Be Knowledgeable. Be Connected.”

Dr. Steve Lohrer, Napa County Office of Education, clarified evidence-based practices, helping parents and caregivers make informed choices about treatment options. Dispelling the notion that evidence-based practice refers strictly to clinical trials, Dr.

Lohrer highlighted the importance of recording observations and thus collecting data regularly to monitor treatment plans: “Write it down as soon as you see it,” he urged, “because you will forget, then you’re thinking, ‘was that last month she did that? When was that?’” Discussing the variety of treatment options, Dr. Lohrer emphasized the need for spe-

cifics: what *exactly* is the treatment intended to do? How well it aligns with the individuals strengths and the family’s values are also critical, as well as measurements for effectiveness.

The afternoon wrapped up with a panel discussion (Alfonso Carmona NBRC, Ron Whitman SCOE, Andrew Baily ANOVA, Lorna Catford CATS, Jeanne Bowman Parent Advocate, and Dr. Vismara and Dr. Firestone) audience members concerned about their children transitioning to adulthood, social skills service needs, and the importance of taking care of oneself. Jeanne Bowman and Lorna Catford acknowledged parents’ needs to network and connect with other parents of children with ASD, highlighting the importance of “friends who’ve been there.”

Lou’s 3 Bs For Change:

Be Involved

Be Knowledgeable

Be Connected

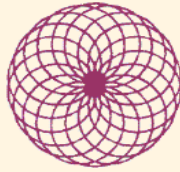


Dr. Matt McAlear and Dr. Patrick Maher (right)

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Mission: The purpose of North Bay Regional Center is to assist people with developmental disabilities or at risk for developmental disabilities in the North Bay Area to obtain services and supports they need to live as other people live in the community.

COMMUNITY & RESOURCE LINKS

Department of Developmental Services

www.dds.ca.gov

Transition to Adult Life: www.dds.ca.gov/WeInclude/JobSeekersTransition.cfm

Health and safety information to individuals with DD
www.ddssafety.net

Appeals, Complaints & Comments:
www.dds.cahwnet.gov/Complaints/Home.cfm#es

Lanterman Act & Title 17: dds.cahwnet.gov/Statutes/LawsRegs/Home.cfm

Early Start Home Page: www.dds.ca.gov/earlystart/
Resource Materials: www.dds.ca.gov/earlystart/ResourceMaterials.cfm#parents

Spanish Resources: www.dds.ca.gov/Spanish/Home.cfm

Sonoma County: www.sonoma-county.org/
Solano County Services www.co.solano.ca.us/services/default.asp

Napa County: <http://www.co.napa.ca.us/>

Social Security: www.ssa.gov/
Supplemental Security Income –SSI: www.ssa.gov/pgm/links_ssi.htm

Benefits for Adults Disabled Before 22: www.ssa.gov/dibplan/dacpage.shtml

Survivor's Benefits: www.ssa.gov/ww&os2.htm
Employment Support for Young People: www.ssa.gov/pubs/10026.html#employment

Office of Special Education & Rehabilitative Services:
<http://www.ed.gov/about/offices/list/osers/osep/index.html>

The Riot(Rights & Advocacy): www.hsri.org/leaders/theriot/index.html National Conversation on Healthy Relationships CD-Rom Available

CONSUMER INFORMATION

Governor Brown's Revised Budget

<http://www.ebudget.ca.gov/pdf/Revised/BudgetSummary/FullBudgetSummary.pdf>

DDS Budget Final Proposal

<http://www.dds.ca.gov/PublicForums/Index.cfm>

Legislative Analysts Office (LAO) Budget Reports

<http://lao.ca.gov/laoapp/PubDetails.aspx?id=2482>

http://lao.ca.gov/analysis/2011/budgetlist/DDS_savings_proposal_review.pdf

Governor Jerry Brown

State Capitol, Suite 1173 Sacramento, CA 95814 (916) 445 - 2841

www.gov.ca.gov click "Contact"

Becoming Independent Family Resource Center

www.becomingindependent.org/family_resource_center.html

ParentsCAN Family Resource Center

www.parentscan.org/newsevents.html

Matrix Family Resource Center

www.matrixparents.org/2-services/index.php

What we do for ourselves vanishes with us; what we do for others remains and is immortal