



HARBOR HAPPENINGS

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DEVELOPMENTALLY DISABLED CITIZENS FACE PREJUDICE IN INLAND COUNTY

Clients and Parents Asked to Speak Out for Equal Rights

*by Karen Kinnebrew, Parent,
President, HRC Board of Trustees*

Last Spring, the news media reported some disturbing events in Inland County, where Inland Regional Center had



*Karen Kinnebrew,
President, HRC Board
of Trustees*

attempted to establish a community home for four men with developmental disabilities. The men had been living in a State Developmental Center, and their histories had involved some type of sexual offense in the distant past – decades ago in some cases. A judge had determined that these men no longer posed a threat to others, and with appropriate care and supervision, deserved the chance to live in a group home in the

community. Inland Regional Center was ordered to create that home, and they did so following all pertinent laws and regulations. What was shocking was the reaction of the community surrounding the home, together with certain members of the media. Unfortunately their fear and mistrust grew to include people with developmental disabilities in general, and evolved into horrifying displays of prejudice, animosity and threatened violence so great that the state stepped in and halted the planned move of these four men to protect their safety.

STATE BUDGET UPDATE

How Does the New Budget for 2004-05 Impact Regional Centers?

The Budget for 2004-05, approved by the state legislature and signed into law by Governor Schwarzenegger includes several new and continued cost-containing measures, designed to slow down the rapid growth which has been seen in expenditures for developmental services over the past several years.

At first glance it does appear that Regional Center services fared very well during such difficult economic times, with an 11% total dollar increase for Regional Center services statewide. This does acknowledge the projection of approximately 10,000 new clients who are expected to enter the program in the coming year. However the major portion of this increase is allocated to provide vocational habilitation services which had previously been provided under the State Department of Rehabilitation, but were transferred to the Regional Centers as a way for the state to cut costs.

Regional Centers' budgets also contain unallocated reductions of \$7 million in Purchase of Services and \$5 million in funding for direct services and operations. At Harbor Regional Center, our share of the unallocated reduction to Purchase of Services amounted to \$253,709 (or about 1% of our total budget). Total cuts to HRC direct services and operating costs, including the full year impact of reductions made last year and this new fiscal year, amount to approximately \$700,000 unallocated

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*Developmentally Disabled Citizens
Face Prejudice in Inland County
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At that time, the Executive Director of Inland Regional Center sent a message to her community:

"I am certain that many of you have been devastated by the insensitive and cruel remarks generalized to all people with developmental disabilities. Now we are attempting to place women who do not have criminal histories in the home, but

still the protesters remain. While we continue in our efforts to dialogue with members of the community, we are firm in our intent to insure that people with a developmental disability can live in a community of their choice." Mary Lynn Clark, Executive Director, Inland Regional Center

Now we are sad to report that members of another community in the Inland County area, in the City of Norco, are behaving similarly towards homes for people who simply have developmental disabilities. The Lanterman Act reads "Persons with developmental disabilities have the same legal rights and responsibilities guaranteed all other individuals by the United States Constitution and laws and the Constitution of the State of California." Despite the fact that state and federal

laws have long established that individuals with developmental disabilities have the legal right to live in typical homes in typical communities, others are mounting a campaign to block their right to do so. Today...in this day and age.

The local newspaper, The Press Enterprise reports, "Once-friendly neighbors started yelling at unfamiliar cars, bricks and stones were thrown through

windows, menacing posters were plastered on every tree and pole." Neighbors claim that the presence of homes where the residents have developmental disabilities will lower their property values and prevent them from ever selling their home. They express fear that people with developmental disabilities will pose a threat to their children. They have gone so far as to engage in repeated acts of vandalism towards the homes, causing at least one service provider to cancel plans to provide home care for clients in that community, and sell her home. "Around the region, there has been a resurgence of extreme discrimination based on stereotypes and gross generalization about people with developmental disabilities," Inland Regional Center told the Press Enterprise.

As stated by one parent, Greg Nicholson, "You may be thinking this is just Norco, and that attitude will never impact MY child. Think again." Mary Feringa (parent of a 33-year-old woman with mental retardation) adds, "The horrible things they are saying, they are saying about my daughter, too, because she is disabled."

Parents in the Inland Regional Center area are organizing their own campaign of phone calls and letters to their legislators, urging them not to be swayed by the voices of those who are driven by fear and prejudice, but to protect the rights of people with developmental disabilities to live in the community. Harbor Regional Center urges you to join them, by contacting your own local legislators.

Together we can make a difference on behalf of people with developmental disabilities, regardless of the community in which they choose to live. A list of your local legislators and how to reach them can be found on the HRC Website, at www.HarborRC.org, in the section entitled Guide To HRC/Budget Alert, or are available by mail upon request by contacting the HRC Resource Center at (310) 543-0691. ■

"It's up to us to make our voices heard. Educate the public that people who have disabilities are not guilty of any crime. We are ALL individuals with far more in common as human beings than any label can describe. I urge you to show support for the regional center on this matter, because they are making a strong effort to stand up for our kids and their right to live, love, work and play in the neighborhood of their choice."

Greg Nicholson, parent

reduction plus \$1.5 million for a reduction of our intake and service coordination staff-to-client ratio.

Despite these reductions, Regional Centers have been given two major new responsibilities. The first is the vocational habilitation services program already noted above, in which regional centers will now coordinate work-related services. At HRC, virtually our entire net increase in funds for Purchase of Services is for this new program. Although no operations funds were provided for additional staff to absorb this new mandated workload, we have been working closely with our clients and the service providers who provide these vocational services, to provide closer and more streamlined coordination of these services.

A major new responsibility for Regional Centers is the implementation of the Family Cost Participation Program, requiring us to begin collecting income information from families of children ages 3 through 17, and assessing a percentage share-of-cost for those families if they receive respite, day care, or camping services and have an income which is above a minimum of 400% of the federal poverty level. (Refer to accompanying insert).

In September, our community leadership committees and Board of Trustees approved a 2004-2005 Expenditure Plan Proposal which is now under review in Sacramento, regarding how we will achieve our required reduction of \$253,709 in Purchase of Services. This plan, which is available for review on our Web site at www.HarborRC.org, indicates that we will continue to implement the successful cost-effective practices which we have put in place during the past two years of the state's budget crisis. This will allow us to provide services which are within the requirements of our contract and the spirit of the Lanterman Act.

We will continue to carefully review all of our clients' individual service needs, and work earnestly with clients and families to accomplish their goals.

LIVING HEALTHY – HRC PROVIDES INFORMATION AND TRAINING

Harbor Regional Center sponsors many trainings that are designed to give HRC clients, parents or service providers information they may need.

Information about health and mental health services is of great importance to many HRC clients and their families.

HRC sponsored a Mental Health Presentation & Fair in May, and a Living Healthy Workshop in June. Both of these educational opportunities provided a wealth of information on mental health concerns, as well as experts in the field who were available to answer any questions the participants had. Topics included an in-depth look at medications with an emphasis on psychotherapeutic medications, the signs of depression, and how to deal with separations and transitions. There were also panel discussions to answer questions on various mental and physical health issues.

Mental health services are funded by the Department of Mental Health. To qualify a child or adult must have a qualifying diagnosis which now includes Autism, PDD and Asperger's, be impaired on the basis of this diagnosis and be expected to improve or stabilize from the treatment. Mental health services include group and/or individual counseling, psychological testing, intensive and rehabilitative day care, medication support and case management including referral, placement and monitoring.

Future trainings and workshops are listed in the HRC Training & Events Catalog mailed twice a year to your home, available by request from your HRC counselor, or available on-line at www.HarborRC.org.



(top) HRC Dental Coordinator, Marcey Brabender dispenses dental wisdom for an interested party. (bottom) Participants at the Living Healthy-Staying Healthy Workshop.

HRC KIDS HAVE FUN AFTER SCHOOL

This afternoon, the YMCA at Arnold Elementary School in Torrance is busy with a craft project. Among the children eagerly working on their masterpieces are children with developmental disabilities with support provided by Easter Seals.

A few miles away, middle school and high school students are learning how to access computers or preparing a new recipe through Social Vocational Services' Link program.

The Easter Seals after school support program and the Social Vocational Services' Link program give HRC children with developmental disabilities opportunities for friendships and recreational experiences outside of school.

Harbor Regional Center works with service providers like Easter Seals providing support staff when needed to allow children to participate in after-school programs with their typical peers. Currently, Easter Seals is serving 29 HRC children at 15 different community after school child care sites. Easter Seals' goal is to work with each childcare site to make sure that the children have a good time and interact with their peers. Erica Doherty's mother, Caroline

enrolled her daughter at the YMCA at Arnold Elementary School so that Erica could have the chance for interactions with other children her own age. Erica has done very well at the YMCA with the extra support and guidance from the staff at Easter Seals. The other children were very receptive to playing with Erica, and Erica even began initiating some interaction with them.

Each month, Serafin Avila, Program Director at the SVS Link program sits down and develops a monthly schedule, based on the interests of the kids attending the Link program. There are many clubs to choose from, including computers, arts and crafts, cooking, sports and even a fashion club. Additional clubs may be developed as the children express interest in a certain activity. The clubs' primary emphasis is promoting personal and social growth through new experiences and choices.

According to her mother, the Link program has been a wonderful experience for 12-year-old Shin-Juan Tsay. Recently, Shin-Juan was able to make a pizza for the first time and was so proud of herself that she couldn't wait to share the experience with her mother. The Crafts Club is a favorite and Shin-Juan has become accomplished at creating gifts for her sisters. Sulan Tsay believes that the Link program offers her daughter many choices and gives her a sense of achievement. "It is a good thing for a parent to see their child smiling and so happy." Sulan adds.

Giving kids a sense of accomplishment and social opportunities is the focus of both the Easter Seals and the SVS Link programs. For more information concerning either of these programs, contact your HRC counselor. ■

Erica Doherty and Emily Lopez share fun and friendship at the YMCA program at Arnold Elementary School.



(middle) During an outside break, Anthony Lopez and Sonak Tank enjoy the slide at the Arnold Elementary YMCA program. (bottom) Link Program staff April Kim assists Keenan Crawford, Roxanne Garcia, and Shin Tsay with a favorite art project.

FAMILY *matters*

A FAMILY DETERMINED TO FACE AUTISM

By Andrea Dougherty, HRC Parent

My son Joaquin is the most loveable child you will ever meet. He enjoys the outdoors, swimming, computers, singing songs, and greeting new people. Joaquin is five years old and diagnosed with autism. When Joaquin was a baby he smiled and loved to give hugs and kisses. Joaquin was 18 months old when he had two febrile seizures, stopped breathing and was admitted to the hospital for three days. Our pediatrician suspected a delay in Joaquin's overall developmental growth, sending us to speech and hearing evaluations before delivering the diagnosis of autism. I was glad to finally know what we were facing and was determined to do everything I could to assist my little boy.

Not having a clue what autism was or why my son was diagnosed with it, I began a journey of denial, finally leading to acceptance. In the months following Joaquin's diagnosis I spent much of my time searching the Internet, as well as contacting different support groups for information. I scheduled an assessment with our local school district which led me to Harbor Regional Center. The more knowledge I acquired the more comfortable I became.

My HRC counselor became a wonderful advocate for me and was there to give me support. An HRC Family Meeting which included a psychologist, speech therapist, and our counselor, was initiated to address my questions and concerns. With the recommendation of the HRC team, Joaquin began receiving Applied



Joaquin and his mother Andrea Dougherty.

Behavior Analysis therapy at home. The therapists worked with Joaquin with self-help skills and being able to go out in the community without behaviors.

At three years of age, Joaquin was placed in a special education classroom but had a tremendous fear of school and would tantrum, cry or run away. To assist Joaquin to successfully attend school, the Long Beach Unified School District and I decided to institute an additional home program using ABA. His therapist taught him ways to control his self-stimulatory behavior, and with time we could even enter his school without an incident. Within five months, I was able to drop Joaquin off at school with more and more successful days.

Joaquin has accomplished so much in the last year. He now attends his Special Day Class and he is able to participate in all classroom activities. He communicates using three to four word sentences, responds to simple questions, and his tantrums are so infrequent that I can't

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Joaquin Gonzales learns to identify body parts, as well as following directions with the help of Autism Spectrum Therapy staff member Rachel Baraona.

*A Family Determined to Face Autism
(continued from page 5)*

even remember when the last one occurred. We are able to go on family vacations, eat at restaurants, play at the park or go to a store. He is even able to stay overnight at his father's home. Joaquin's little sister Linda loves to play with her brother, who now acknowledges her and even initiates play.

In May, I took Joaquin to Sesame Street Live. I wasn't too sure how he would react, but to my surprise he absolutely loved it. He was dancing and singing along to his favorite characters just like all the kids around him. I am extremely proud of my son and all his amazing accomplishments. My son is my inspiration, and at only five years old I can't wait to see where this path will lead us. ■

RECOGNIZING EXTRA EFFORT!

HRC is dedicated to providing **support, information and choices** to our clients and their families. Our staff, from the receptionists to our psychologists, strive to demonstrate our core values through their interactions with you.

You can help us recognize those individuals who have provided you with outstanding care and service. When you see an HRC staff member who is **demonstrating respect by treating people considerately, working collaboratively, looking for ways to be helpful, responding quickly and explaining any delays, listening, sharing information, or any other assistance you found helpful**, simply fill in this form and mail it to:

Kathy Scheffer, Public Information Specialist, 21231 Hawthorne Blvd., Torrance, CA 90503 or by e-mail at kathryn.scheffer@HarborRC.org

We will make sure that the HRC Counselor, support staff, clinical staff, Resource Center staff or other members of the HRC team receive your note along with our special recognition.

Name of person you wish to recognize: _____

Your name: _____

How that person demonstrated outstanding service or fulfillment of our core values: _____

We appreciate your support in helping us acknowledge these outstanding individuals.

MEET YOUR BOARD

Harbor Regional Center's Board of Trustees member Kristine Engels has a special relationship with many adults with developmental disabilities. As Program Manager for LifeSteps Foundation, she is busy with the responsibility of overseeing 12 programs and serving clients from four different regional centers.

This remarkable woman started her career with children and adults diagnosed with developmental disabilities at Fairview Developmental Center in 1968. A Girl Scout leader who needed a volunteer project, Kristine approached Fairview and has never looked back. She became a Recreational Leader at Fairview, planning recreational outings for the women who lived there. "It was like an epiphany, I knew I belonged here," she says. No challenge was insurmountable. When a beach outing was threatened to be canceled because of lack of staff, Kristine enlisted her neighbors and friends to obtain enough support. "It was the most amazing thing," Kristine states. "For some of these girls it was their first outing, and for most their first trip to the ocean." At this time Kristine and her husband became sponsors for two young girls living at Fairview providing clothing, birthday and holiday gifts and other needed items.

The birth of her son, who had physical and learning problems, brought Kristine a more personal view of her life's work. Her son is now married, has two kids and owns his own business, but through his experiences Kristine became an even

more dedicated advocate for her clients. This kind of dedication and can-do attitude is indicative of Kristine. Becoming involved is just second nature; she has participated in the HRC Service Provider Advisory Committee for 7 years and serves as their chairperson. She also serves on the Client Services and Client Advisory Committees. When asked to join the HRC Board of Trustees in 1999 to represent the service providers, Kristine eagerly accepted.

Kristine is also innovative, joining HRC to develop the Harbor Friendship Center – with help from an HRC resource development grant – which has become a model for other social programs. This Center is a place where adults with developmental disabilities participate in positive, meaningful and safe social experiences.

Kristine has seen many positive changes since she began working with LifeSteps and Harbor Regional Center. Working with HRC on the Service Provider Advisory Committee has allowed for increased communication and education between service providers and HRC. As a result, a tremendous spirit of cooperation between HRC and service providers is present. Kristine ends her term of service on the Harbor Regional Center board next year, but will always be dedicated to assisting the clients that she embraces. ■



HRC Board of Trustee member Kristine Engels (right) assists HRC client Linda Fox with planning her monthly budget.

Issues of Harbor Happenings
can be found at the
Harbor Regional Center
World Wide Web site at

www.HarborRC.org

USING INSURANCE EFFECTIVELY

Families of a child with a disability or special health care need usually rely on insurance more often than others. Although health insurance can be complex, knowing how to use it effectively can make a difference in obtaining services that will help your child.

In California, Assembly Bill 88 (AB88) applies to most health care service plans and requires that all such plans provide coverage for the diagnosis and treatment of “severe mental illness,” as they would for any medical condition. The definition of severe mental illness under AB88 includes autistic disorder, Rett’s disorder, Asperger’s disorder and pervasive developmental disorder, not otherwise specified. What this means is that most families’ medical plans should pay for “medically necessary services” required to diagnose and treat autism spectrum disorders. Some of the services that may be considered medically necessary are speech therapy, OT, PT, intensive behavior services and communication devices for non-verbal children.

There are a few simple tips to better access and work with your healthcare plan:

- Obtain a copy of your insurance contract or certificate of coverage. Understand what is covered, especially the parts that address the services that your child needs. There should be a section with definitions to help you understand particular phrases or terms. There will also be a section to explain the appeals process.
- Insurance is designed for medically necessary services; therefore you must have a doctor’s order for any services that will be billed to your insurance. Many insurance companies offer case management services, and you may find it helpful to request an insurance case manager to assist you.
- You should understand basic information about your plan. Know when and if you need referrals from your child’s primary doctor, any limits on services such as therapies, when you are required to make co-payments and pay

deductibles, and what and if there are yearly or lifetime caps on the insurance.

- Learn about your health plan’s appeal process. If your insurance denies a service you should appeal. If your insurance company denies a request to pay for a service, they will send you a denial notice containing the information you need to appeal the decision. A rule of thumb – always base your appeal on the reason given by the insurance company for the denial.
- Be prepared to work with the specialist the health plan provides. It is very likely that your health plan will have professionals that are experts in the treatment requested. And you will probably have to accept the professional the health plan offers, unless you can make a very compelling argument about why the provider you want is superior to the one on the health plan’s network.
- Because you might receive different answers from the people you speak to from your health plan, always get the name of the person you talk to on the phone. It is very important.
- A health plan must meet your needs, and cannot deny your request for a service because there are no specialists on your health plan’s network that provide the service you are seeking. If your plan doesn’t have an appropriate provider, they should assist you to find one and pay for any medically necessary care.
- Learn about California’s Independent Medical Review program. If you have been unsuccessful with your health plan’s appeal process you may request an Independent Medical review of your health plan’s denial of your claim. This review is conducted by physicians and other healthcare professionals who are not affiliated with the health plans they review.

For more information about your rights as a member of a health plan in California, go to the web site, www.calpatientguide.org or obtain the HRC publication, “Obtaining Third Party Health Insurance Coverage for Autism Services” from your HRC counselor, from the HRC Resource Center or on the Web at www.HarborRC.org in the publications section.

Client focus

A PASSION FOR LIFE

Harbor Regional Center client Paul Haigazian has written a book whose title describes his philosophy on life. In *Bitter or Better* Paul describes the trials and tribulations he has experienced and why he has chosen to be a better person instead of a bitter one. When Paul was born it took doctors over six minutes to get him to take his first breath. Though his parents were told at the time of his birth that Paul would be fine, at seven months old he was diagnosed with severe Cerebral Palsy. As Paul writes in his book, "In the early 1950's, institutionalizing or isolating rather than mainstreaming the disabled was the socially accepted way to go." Paul's parents refused to place him in a residential facility and took him home to an uncertain future.

This unique situation required locating someone who could help...a huge endeavor in those days. Fortunately, a friend directed them to Dr. Margarita Jones, a pioneer in Cerebral Palsy research and therapy. Five days a week, Ann drove Paul to Childrens Hospital in Los Angeles for therapy.

During his teens, Paul began rebelling and blaming his mother for his disability. Things started to change, Paul relates, "When I decided to stop the pity party and began to appreciate what I had." As time passed, Paul's speech became less slurred allowing him to communicate better and he became more stable on his feet allowing for more mobility. He began taking accelerated classes, wrote articles for the high school newspaper, formed long-term relationships and graduated from high school.

Paul is now 52 years old and has earned a Master's degree in psychology from

Pepperdine University. He has come far from the boy that was only allowed to attend special education schools, segregated from nondisabled children. In fact, when Paul attended community college in 1969, it was his first experience being in school with nondisabled peers.

Paul also became the first disabled person to graduate from El Camino College. "When I started college I was a bit intimidated..." Paul continues, "I thought to myself, I could live in fear or get my degree. I chose to get my degree." At that time there were no Disabled Student programs, consequently, supports for students with special needs were not available. When Paul started school many of the teachers were wary to include him in their classes. By the time he graduated, school had become a positive experience for Paul, the other students and the teachers.

Paul lives by the philosophy his parents taught him...never to use his disability as an excuse and give back to others who are less fortunate. Paul uses his knowledge and experience, via e-mail and the Internet, to correspond with others in a position similar to his. He also speaks to many parents who have a child with a disability giving them hope and information. Paul refuses to say "poor me" and plans to continue to assist others as long as he is able.

You may obtain a copy of Paul's inspirational book at the HRC Resource Center or at his Web site: www.bitterorbetter.walton.com. The book is also available as an e-book at no cost by e-mailing your request to paulhaigazian@yahoo.com. ■



Paul Haigazian stays busy writing and e-mailing others offering support and information.

resource center

WHAT'S NEW AT THE RESOURCE CENTER

By Dominique DeBorba, HRC Parent & HRC Resource Center Family Support Assistant

Research has shown that friendships and good social skills not only shape all aspects of emotional and intellectual growth, but are also vital to our children's future success and happiness. For some HRC clients, making friends can be challenging and a little extra support and assistance is needed. We now know that family support, regular schooling, and community living programs are not always enough to facilitate friendships or social experiences. At the HRC Resource Center, we have a large section of information on relationships and friendships. This month I'd like to highlight some new and old favorites:



The Friendship Factor by Kenneth H. Rubin, PhD

With his honest, empathic and pragmatic approach, Dr. Rubin demystifies what makes some children well-liked and accepted by peers, while others are not. The book also teaches parents ways to support their kids to become socially adept.

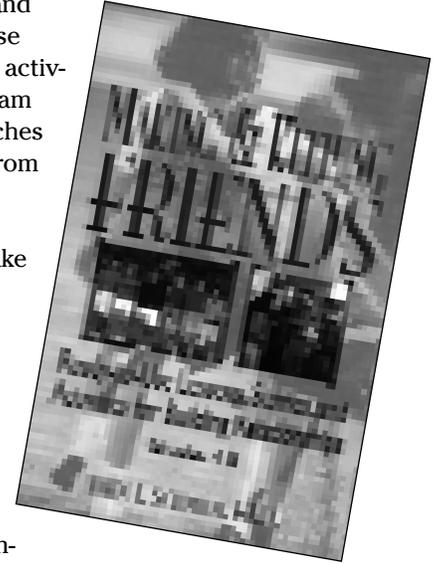


Good Friends Are Hard To Find by Fred Frankel, PhD

This step-by-step guide teaches parents how to assist their children, ages 5 through 12 years old, to make friends and solve problems with other kids. This guide also offers strategies for the child who is dealing with teasing and bullying.

Making & Keeping Friends by John J. Schmidt, EdD

A unique and ready-to-use sequential activities program which teaches students from grades 4 through 8 how to make and keep friends. A specific method is presented for creating and developing relationships and places responsibility on the individual student to create "messages" that invite friendships.



Becoming Acquaintances or Friends by Perry Samowitz



This videotape was designed to provide building tools and techniques to help young adults with developmental disabilities make and keep friends. To aid the viewer to understand different relationships and scenarios, the video is filled with different scenes illustrating how to distinguish the behaviors between strangers, acquaintances, and friends. ■

GOING BACK TO SCHOOL

By Rita Eagle, PhD, HRC Clinical Psychologist and Pat Zalenski, RN, HRC Nurse

A new school year has begun. If you stay prepared, become knowledgeable about health and safety issues, acknowledge and handle stress and anxiety, and communicate with your child, then you can promote a more healthy and happy attitude about learning. Here are some simple tips for handling the health and safety needs for your child:

- Especially for children at high risk, check with your pediatrician about availability of flu shots.
- Even during the school year, it is very important to remember to protect the skin from the harmful rays of the sun by continuing to apply sunscreen.
- Check in advance to make sure immunizations are up to date. Many children may need a booster shot or a TB test.
- Allow time in the morning for a good breakfast. The brain requires nutrition for concentration and learning to take place. A good breakfast may include unsweetened cereal, milk and a piece of fruit (1% or nonfat milk may be chosen if weight is a concern.) An egg and toast with fruit or a bagel with cream cheese or yogurt are other choices.
- Think in terms of healthy snacks and lunches as well. Fresh fruit is a better choice than fruit juice. A sandwich and vegetable or cheese sticks, popcorn and pretzels are nice healthy choices.
- Enough sleep, good nutrition and plenty of exercise will help success in school.
- Teach children good health habits including the importance of body cleanliness.

For parents and kids, back to school is a see-saw of highs and lows. Let your child know how much you value his education, and that, even if you are not with him or her, he is in your thoughts and you are still looking out for him. Relieve anxieties and heighten the chances of a positive school experience:

- Bedtime should be unrushed and early enough to provide the child adequate sleep. A bath and a bedtime story will help to promote relaxation and together time.
- Provide a structured time and space for homework. Provide your child with his/her own space and own materials to promote increased self-esteem and a sense of worth.
- Parents should be involved from the start. A child should see that the parent and teacher know one another so that there is a connection between home and school.
- Attend parent teacher nights, and IEPS.
- Keep up communication with your child's teacher and let your child know the good things his teacher said about him.
- Make sure you know what he is doing in school, that you agree with it, and there is follow through.

Then let your child know that his coming home is important, too. Always arrange a time when you ask about the day in school. Help with homework as needed. If you can't, arrange for someone else to help. And if that is not possible either, let the teacher know about the constraints, so she or he can understand your child's situation, and make allowances if needed. Remember, your support and interest in his school day will help make school a positive experience for your child. ■

EVENTS

Friends and Family Event

WOW!! Despite the hot July weather and warnings of virus-carrying mosquitoes, 1600 clients, family members, service providers and staff enjoyed HRC's Family and Friends Celebration at El Dorado Park on Saturday, July 24th. Whether climbing, bouncing, and sliding on giant inflatable obstacle courses, joining in a lively game of "Wrap-Your-Mom-In-Toilet-Paper" with *The Original Party Masters*, swaying along with the Pua Nani Polynesian Dancers, serenading the crowd in the Karaoke tent, snacking on hot dogs, shaved ice, popcorn and cotton candy, or adorning themselves with face painting, balloon hats, handmade visors and leis...everyone had a great time!



Friends & Family Event, 2004

- Kids' Craft Table (leis) by AbilityFirst
- Face Painting & "Space Buggy" Bounce by Birth and Family Services
- Karaoke Tent by Cambrian Homecare
- Transportation by Diversified Paratransit, Inc.
- Kids' Craft Table (Sun Visors) by Easter Seals of Southern California
- "Nater the Inflator" Balloon Art by Inclusive Education & Community Partnership

Harbor Regional Center would like to thank the following sponsors who generously brought you the following fun activities:

- Face Painting, "Super Caterpillar," "Obstacle Course," and "Jumper-Climber-Slide" by Kings Harbor Church youth volunteers
- Transportation aides by LifeSteps Foundation, Inc.
- Hot dogs and snacks provided by Northrup Grumman
- "Chopperville" Bounce by Pediatric Therapy Network
- Pua Nani Polynesian Dancers (with thanks to HRC's Valerie Dawson and family)
- Soft drinks and snacks by the Sandpiper Foundation and "Sand Debs" youth volunteers
- "Scooby Do" Bounce by Shield Healthcare
- Balloon Animals by Mr. and Mrs. Bernie Slotnik, HRC Parents



Fluor Backpack Campaign

Community partners are an invaluable asset to Harbor Regional Center and the approximately 9000 clients that we serve. The Fluor Corporation recently donated over 300 brand new backpacks to Harbor Regional Center children who were in need. These backpacks were given to children in 1st through 6th grades and were filled with notebooks, pencils, pens,



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Events

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paper, rulers, markers and all the other things a child might need to start the school year off right. Employees from Fluor and Harbor Regional Center staff distributed the backpacks at the Harbor Regional Center Training Center in Long Beach to more than 100 excited children. The Fluor Corporation also provided snacks and drinks for the kids. HRC counselors delivered the remaining backpacks to children on their caseloads. Harbor Regional Center would like to thank the Fluor Corporation for their generosity and all the work it took to put together this wonderful program. ■



Fluor Backpack Campaign



REACHING OUT TO THOSE IN NEED DURING THE HOLIDAYS

The holiday season is fast approaching and for many of us it will be a time to spend enjoying family and counting our blessings. Many children with developmental disabilities face the holidays without that special dinner or a new toy. These families are struggling just to feed and clothe their children and the holiday season is not one of joy but one of sadness. For more than 30 years, Harbor Regional Center has given our most needy families a little extra support during the holiday season. We could not do this if it weren't for the generosity of individuals, businesses, and foundations in the community.

You can assist these children and their families this holiday season in several ways. By a tax-deductible cash donation to Harbor Help Fund, disadvantaged children and their families receive food

and/or gift certificates to purchase a holiday dinner and a new toy or clothing item. Many individuals or businesses participate in the "Adopt-a-Family" program where a benefactor is matched with a family in need and purchases toys and other items for their assigned family. Many sponsors of the "Adopt-a-Family" program receive great joy in delivering their gifts personally to their adopted family during the Holidays.

According to Julie Miranda from Fluor Corporation, "These programs make a real difference to a child's life and, frankly, give Fluor employees a new appreciation for the spirit of the Holiday season." If you want more information about how you can assist a family during the holidays, contact Kathy Scheffer at (310) 543-0686 or at kathryn.scheffer@HarborRC.org. ■



HEALTHY SKIN

The following is an excerpt from The Safety Net Newsletter. You may access future editions online at www.ddssafety.net.

Many of us take healthy skin for granted, until we have a problem that becomes difficult to treat. Why is healthy skin so important? It is important because our skin protects our bodies in several important ways including protecting us from disease and infection, maintaining the temperature inside our body and sensing pain, pressure, heat and cold. *Changes in our skin can tell us important things about the conditions inside our bodies. Our skin condition can indicate if we have problems with nutrition, hydration, circulation, infection, and disease. People with developmental disabilities may have certain conditions or situations that make it more likely for skin problems to develop.*

There are a variety of important factors that can affect or influence the condition of a person's skin. Awareness of the following factors can help with prevention and early detection of problems that may require treatment:

- **Nutrition:** Skin problems are more likely to develop in people who have a poor or inadequate diet, including insufficient intake of fluids.
- **Hygiene:** Maintaining clean skin prevents bacterial contamination that may otherwise lead to infection.
- **Moisture:** Frequent moisture or dampness may cause irritation, rashes, and skin breakdown. People who excessively perspire or who are incontinent may be especially at risk. It is important to make sure that clothing and bedding are kept dry.
- **Mobility:** Limitations in mobility may lead to skin problems that result from continued pressure on the skin from underlying surfaces, lack of circulation, and friction. Frequent changes in body

position are necessary. Some people may need assistance from others to change body position at least every two hours.

- **Age:** As we age, skin becomes thinner and drier, bruises and chaps more easily, and heals more slowly. Mild soaps and lubricating lotions may be needed.
- **Medications:** Many widely used medications may cause an increased sensitivity to sunlight resulting in rashes, hives, and sunburn. Medication bottles should be checked for warning labels. Use of sunscreen and protective clothing while outdoors is useful in protecting skin.
- **Medical conditions:** The presence of other medical conditions such as diabetes or hypothyroidism may contribute to a variety of skin problems. Your health care professional can alert you to any special risks.
- **Responses to discomfort:** For people with a developmental disability, a sensory impairment may limit the ability to feel pain or discomfort. In addition, he or she may not clearly communicate these feelings to others. As a result, skin problems may develop because warning signals are not recognized.
- **Assistive and supportive devices:** The use of special devices that contact the skin may cause problems if the device does not fit properly, if it traps moisture, if it places too much pressure on the skin, or if it rubs the skin. It is important that these devices be checked frequently to ensure that they fit well and are being maintained in good condition.

Making sure skin remains healthy is an essential part of maintaining good health. Talk to your health care professional whenever there are changes in skin condition. ■

USANDO EL SEGURO MEDICO EFICAZMENTE

Familias de niños con incapacidades o necesidades medicas especiales usualmente dependen mas seguido que otras familias. Aunque el seguro medico puede ser complejo, sabiendo como utilizarlo eficazmente puede hacer la diferencia en obtener servicios que benefician a su niño/niña.

En California, El Proyecto de Ley de la Asamblea 88 (Assembly Bill AB88) aplica a la mayoría de los seguros médicos y requieren que tales planes provean cobertura para diagnósticos y tratamientos de “problemas mentales severos”, como cualquier otra condición medica. La definición de problemas mentales severos bajo AB88 incluye desorden autismo, desorden Rett’s, desorden Asperger’s, y desorden del desarrollo generalizado (PDD) si no es especificado. Lo que significa que muchos planes médicos de familias deberían pagar por “servicios médicos necesarios” requeridos para diagnosticar y tratar desordenes entre el espectro de autismo. Algunos de estos servicios pueden ser considerados médicamente necesarios tales como terapia de lenguaje, OT, PT, servicios intensivos de comportamiento y equipos de comunicación para niños sin lenguaje.

Existen unos cuantos consejos simples para seguir y obtener mejor acceso para trabajar con sus planes médicos de salud :

Obteniendo una copia de su contrato con su seguro medico o certificado de cobertura. Entender lo que cubre, especialmente las partes que se aplican a las necesidades de su hijo/hija. Debería haber una sección con definiciones para ayudarlo a entender ciertas frases o condiciones. También debe de haber una sección para explica el proceso de apelación.

Su seguro medico es designado para servicios médicos necesarios; entonces usted debe tener una orden medica para cualquier servicio que será cobrado a su seguro medico. Muchas compañías de seguro medico ofrecen servicios de manejo de su caso para individuos con necesidades medicas complicadas o incapacidades. Su familia podría beneficiarse pidiendo que un consejero de su seguro le ayude a manejar su seguro efectivamente.

Es especialmente beneficioso entender la información básica acerca de su plan. Saber cuando y si necesario tener referencias del doctor particular de su hijo/hija para ver a un especialista o recibir servicios de exámenes especiales o tratamientos, cualquier limite de servicios tales como terapias, cuando usted necesita hacer pago por visita y pagar deducibles, y que si tal vez tienen limite anual o limite de por vida en su seguro.

Aprenda a cerca del proceso de apelación de su seguro. Si su seguro le niega los servicios usted deberá apelar. Porque muchas familias tiene éxito con el proceso de apelación, vale la pena probar. Si su seguro medico le niega pagar por servicios médicos, ellos deben de mandarle un aviso de denegación conteniendo información que usted necesita para apelar la decisión. Una regla a seguir siempre es de basar su apelación en la razón expuesta por su compañía de seguro para su denegación.

Este preparado para trabajar con proveedores especialistas que su plan de seguro medico le provea. Es muy posible que su seguro de plan medico tenga su propia red de profesionales que son expertos en el tratamiento requerido. Sin embargo posiblemente la red no le incluye al especialista que usted quisiera ver. Usted posiblemente tendrá que aceptar al profesional que el plan le ofrece, solo que usted pudiera tener un argumento incontestable porque el proveedor que usted quiere es superior a de la red su plan medico.

Siempre apunte el nombre de la persona que usted habla por teléfono. Porque usted pudiera recibir diferentes respuestas de la persona con la que usted habla de su seguro medico, es muy importante de escribir los nombres de cualquier persona con la que usted hable.

Un plan medico debe de satisfacer sus necesidades. Un plan no puede negarle sus servicios solo porque no tienen un especialista en su red de profesionales en su plan de seguro medico que provee los servicios que usted esta solicitando. Si su plan no tiene un proveedor apropiado, ellos deberán ayudarlo a usted a encontrar uno y pagar por cualquier cuidado medico necesario.

Entérese acerca del programa de Análisis Medico Independiente de California (California’s Independent Medical Review program) Si usted no ha sido exitoso con su proceso de apelación de su plan medico usted puede pedir un análisis Medico Independiente de la denegación de su reclamo a su plan de seguro medico. Este análisis es conducido por médicos y otros profesionales de salud que no están afiliados con los planes de salud que ellos evalúan.

Para mas información acerca de sus derechos como un miembro de plan de seguro medico en California, vaya a la pagina de la Internet, www.calpatientguide.org u obtenga su copia de publicación del HRC, “Obteniendo Cobertura Medica de unas Terceras Personas para servicios de Autismo” de su consejero de HRC, del Centro Informativo del HRC o en la pagina de la Internet, www.HarborRC.org en la sección de publicación. ■

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BOARD MEETINGS

2004

November 16, 2004 – 6:30 p.m.

No meeting in December

2005

January 18, 2005 – 8:00 a.m.

February 15, 2005 – 6:30 p.m.

March 15, 2005 – 8:00 a.m.

April 19, 2005 – 6:30 p.m.

The Board of Trustees of the Harbor Developmental Disabilities Foundation, Inc. meets regularly once a month on the THIRD Tuesday of the month.

Board meetings alternate between morning and evening times to provide opportunity to people in the community to participate. Morning meetings are from 8:00 a.m. to 10:00 a.m. and evening meet-

ings are from 6:30 to 8:30 p.m. The Board does not meet in June, August or December.

All regularly scheduled business meetings of the Board are open to the public and visitors are welcome to attend both morning and evening meetings of the Board. The meetings are held in Conference Room A1 & A2 at Harbor Regional Center. ■

Harbor Happenings is a publication of Harbor Regional Center, a program of the Harbor Developmental Disabilities Foundation, Inc.

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CALIFORNIA FAMILY COST PARTICIPATION PROGRAM

*Governor's new state budget establishes "co-pay"
for parents of children with developmental disabilities.*

On July 31st, the Governor signed a state budget for 2004-2005 which continues his efforts to reduce the state budget deficit. One element of this budget which will have a direct impact upon many HRC families is the introduction of new share of cost fees, called the **Family Cost Participation Program**.

While some details regarding the implementation of these co-pays are still in development in Sacramento, Section 4783 of the Lanterman Act has now been amended to require regional centers to administer this program, beginning in January of 2005, for families who meet certain criteria below.

Who will be required to participate in the Family Cost Participation program?

Families who meet ALL of the following criteria will be affected:

- Have a child or children, ages 3 to 17 years, with developmental disabilities, who live(s) in the home of the parent or parents
- Receive services purchased by the regional center
- Are not eligible for Medi-Cal
- Have an income which is at least 400% of federal poverty level or greater

For families who meet the above criteria, the assessment of co-payments will be applicable to ONLY the following regional center services: respite services, day care, and camping services.

Family Cost Participation level will be determined on a sliding scale.

The Department of Developmental Services has developed a sliding scale for determining each family's amount of co-payment, based upon Adjusted Gross Income which is over 400% of Federal Poverty Level (FPL), and the number of people living in the home. (Adjusted Gross Income is typically found on California Tax Returns Form 540 line 17 or Form 540a line 14 or Form 540EZ line 13.) The state also developed a formula for reducing the percentage of the cost participation fee for families with more than one child with developmental disabilities.

At the time of intake or Individual/Family Service Planning meetings, families will be required to "self-certify" their income, by providing the regional center with a copy of their W-2, payroll stubs, prior year state income tax returns or other documents showing proof of income. Families will also have the opportunity to provide evidence of extraordinary medical expenses being borne by the family, which then may be deductible from total family income in determination of co-payment amounts. Within ten days, the regional center shall be required to notify parents of their cost participation amount for any of the applicable services.

We understand that these new requirements will be unfamiliar, and families may feel reluctant to provide income information

to their Regional Center when this has not been required before. The law now states: "Families who have not provided copies of income documentation...shall be assessed the maximum amount of cost participation based upon the highest income level adjusted for family size until such time as the appropriate income documentation is provided."

Families will be required to pay their required monthly share of cost directly to service providers of their respite, day care or camping services. The law also establishes processes for families to request a redetermination of their cost assessment, if they feel their share of cost has been determined in error.

Harbor Regional Center is awaiting further information and directions from Sacramento regarding this program. We will strive to continue to keep our community as informed as possible as this information is received.

As published in the 2004 Federal Register,
2004 Federal Poverty Level:

Family Unit	Federal Poverty Level	400% FPL*
2	\$12,490	\$49,960
3	\$15,670	\$62,680
4	\$18,850	\$75,400
5	\$22,030	\$88,120
6	\$25,210	\$100,840
7	\$28,390	\$113,560
8	\$31,570	\$126,280

**Families whose income is equal to or greater than the amount in the third column, for their family unit size, will be assessed a share of cost participation percentage ranging from 5% (at the minimum income level of 400% poverty level), to 80% (for the highest income group of 1300% of federal poverty level or greater).*

Families with more than one child served by the regional center will be eligible to have their assessed share of cost amount for each child's services reduced:

Number of Children served by the Regional Center	Percentage Share of Fee Cost
2 children who are clients	75 %
3 children who are clients	50%
4 children who are clients	25%
More than 4 children who are clients	Exempt from cost participation fee

For the latest developments on Family Cost Participation and other important budget information, please check our Web site for periodic updates, at www.HarborRC.org. You are also invited to join our HRC E-mail Network for ongoing e-mail bulletins, by sending your name and e-mail address to Nancy Spiegel, nancy.spiegel@HarborRC.org.

PROGRAMA DE PARTICIPACIÓN DE LA FAMILIA (“CO-PAY”)

Ley del Senado 1103: Acta del Presupuesto del 2004: Salud, por el Comité de Revisiones Fiscales y del Presupuesto añadieron la Sección 4783 a la Ley Lanterman. La ley requiere que el Departamento de Servicios del Desarrollo (DDS) desarrolle regulaciones acerca de como los Centros Regionales van a administrar el Programa de Participación de la Familia en los Costos de Servicios y también la escala que va a ser utilizado para determina el costo a la familia. A continuación está un resumen del lenguaje que fué añadido para determina la cantidad de la participación. [Nota: Por favor, lean el lenguaje actual de esta sección nueva.]

Fecha efectiva: Enero 1, 2005 – Personas Afectados:
Aquellas que tienen **TODAS** las siguientes condiciones:

- Niños de 3 a 17 años
- Tienen una discapacidad del desarrollo
- Viven en casa con sus padres
- Reciben apoyos y servicios **comprados** por el centro regional
- No son elegibles para Medi-Cal.

La cantidad de participación en el costo se aplicará solamente a los servicios de descanso, cuidado durante el día y campamento.

DDS va a desarrollar una escala para las familias cuyo Ingreso Bruto Ajustado (Adjusted Gross Income) sea más del 400% del Nivel Federal de Pobreza (Federal Poverty Level – FPL) y será basado en el número de personas que viven en el hogar. Ejemplo, Publicado en el Registro Federal el 13 de Febrero del 2004, el FPL en 2004 es:

Familia de 2 personas: 2 = \$12,490 (400% = \$49,960)
Familia de 3 personas: 3 = \$15,670 (400% = \$62,680)
Familia de 4 personas: 4 = \$18,850 (400% = \$75,400)
Familia de 5 personas: 5 = \$22,030 (400% = \$88,120)
Familia de 6 personas: 6 = \$25,210 (400% = \$100,840)
Familia de 7 personas: 7 = \$28,390 (400% = \$113,560)
Familia de 8 personas: 8 = \$31,570 (400% = \$126,280)

Por cada persona adicional, añadida \$3,180 o (400% = \$12,720 por persona)

La cantidad de Ingreso Bruto Ajustado de esas personas que pagan impuestos en California se puede encontrar en línea 17 de la Forma 540 de su declaración de impuestos o la línea 14 de la Form 540A o la línea 13 de la Forma 540EZ.)

Por ejemplo: Una familia de 4 personas con Ingreso Bruto Ajustado de menos de \$75,400 no debe contribuir al costo de los servicios.

Para familias que tienen más de un niño recibiendo servicios del centro regional, el costova a ser asesorado de la siguiente manera:

- Familias que tienen 2 niños que reciben servicios del centro regional deberán contribuir 75% del costo de participación.
- Familias que tienen 3 niños que reciben servicios del centro regional deberán contribuir 50% del costo de participación.
- Familias que tienen 4 niños que reciben servicios del centro regional deberán contribuir 25% del costo de participación.
- Familias con mas de 4 niños están exemptas del costo de participación.

Sin excepción, la cantidad de participación en el costo será menos que el costo que los padres tendrían que pagar si el niño vive en cuidado residencial 24 horas al día.

La cantidad de la participación en el costo sera asesorado durante el proceso de elegibilidad y anualmente como part del Plan de Program del Individuo (IPP). Los padres tendrán la responsabilidad de certificar sus ingresos a traves de la Forma W-2, comprobantes de pago de sus ingresos, formas del pago de impuesto or a través de otros documentos de evidencia de ingresos. Los padres tendrán la responsabilidad de notificar al centro regional de cualquier cambio en ingresos que pueda afectar la cantidad tasada.

Una vez que la familia haya completado la documentación necesaria, el centro regional tiene 10 días hábiles para notificar a los padres la cantidad de su participación en el costo.

Si los padres no proven documentación de sus ingresos, se les asesorará la cantidad máxima de la participación en el costo. Si los padres ofrecen prueba de sus ingresos, se les reembolsará la diferencia de hasta 90 días antes de proveer la prueba.

El Director del Centro Regional puede otorgar ajustes a los padres que se encuentren en medio de una pérdida económica catastrófica que impacte directamente a la familia, o costos médicos significativos que no sean reembolsables y que estén asociado al cuidado de un niño que recibe servicios del centro regional; este ajuste será un error en la cantidad de previa presentación de recibos y será redeterminado anualmente.

Los padres pueden apelar participación en el costo a través del Director del Centro Regional durante los primeros 30 días después de la notificación del centro regional. Los padres pueden apelar la decision del Director al Departamento de Servicios del Desarrollo durante los primeros 15 días después de recibir de la notificación del Director – esto puede resultar en una audiencia (hasta 7/1/2006). Después de 7/1/2006, los padres pueden apelar el proceso sin que esto resulte en una audiencia.

Este programa dejará de estar en efecto el 7/1/2009 y será revocado el 1/1/2010, si no hay estatutos nuevos establecidos.

Una vez que el Departamento de Servicios del Desarrollo establezca la escala de participación en el costo, el centro regional les enviará información adicional.