



HARBOR HAPPENINGS

2003 EDITION, VOLUME 2

HRC TEAM MAKES VISITS TO LEGISLATORS

For the last few months, a very dedicated group of clients, parents, service providers, board members, and HRC staff have been making visits to our local legislators, on behalf of our HRC community. For each of seven visits, we assembled a team of representatives from each of these groups, who live within the legislator's service area.

At these meetings we talked about the challenges which regional center clients and families face, and the accomplishments they are making as a result of

services and supports provided through Harbor Regional Center. These services and supports are made possible due to the funding we receive from the state, so, of course,

we want our local legislators to be aware of the tangible positive results we are seeing because of this funding.

At a time when the budget deficit is so great, we know we will be unable to escape some form of reduction. We are

CALIFORNIA'S BUDGET FOR 2003-2004: The Uncertainty Continues

As reported in earlier issues of this newsletter, The California State Budget is facing a deficit of approximately \$35 billion for the coming fiscal year, which begins July 1st, 2003. There is still a high degree of controversy within the legislature, about choosing among the equally unpleasant options of raising taxes, cutting state services, and borrowing against future years in order to balance the budget. In both the State Assembly and the State Senate, committees have looked closely at proposals put forth by the Governor and his administration, and have been given the very difficult task of deciding where cuts can be made. At this time we still face a great deal of uncertainty about what the future will hold for regional center clients.

Regional centers contract with the state, and therefore will not receive state funds until a budget is passed, for the year which begins July 1st 2003. Because recent years' budgets have been delayed as long as two months or more, HRC has had to seek a loan from our bank so that we can continue to provide services in the face of such budget delays. HRC anticipates that we will begin using credit with the start of the new fiscal year, in July, and will be able to continue until as late as mid-September. Our community of clients, families, service providers, and regional center staff are still waiting anxiously to see how soon our legislators and the Governor will be able to reach enough of a compromise to pass a budget.

We do know now that our advocacy efforts for the current year have been successful, and the Department of Developmental Services has secured additional funds for the regional centers for the current fiscal year which ends in June.

*The Honorable
George Nakano,
California State
Assembly*



Jerome Academia and Noah

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*California's Budget for 2003-2004:
The Uncertainty Continues
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This means that regional centers did not face running out of funds, or having to borrow money, or close their doors before the end of June, 2003.

We also know at this point that reductions or reorganization in services to citizens with developmental disabilities are likely to occur:

- The Governor's Budget for 2003-2004 proposed Purchase of Service Standards for regional centers statewide. These standards would go into effect in 2004, and would tell all 21 regional centers what services they are allowed to purchase or not allowed to purchase. At the time of this writing, there appears to be significant opposition to these proposed standards within both houses of the legislature. Some in Sacramento have suggested possible alternatives to this approach, such as payment reductions to all service providers, or 'unallocated reductions' to regional centers' Purchase of Services budgets. (If HRC again receives an unallocated reduction for 03-04, as we did for 02-03, it will again be necessary for our community to decide how to make the required reduction in expenditures.)
- The proposed change to regional center eligibility criteria has received partial support among some of the legislators at this time. This proposal would require the use of the more restrictive federal standard for "substantial disability" when deciding whether a person is eligible for regional center services,
- The proposed addition of a Parental Co-payment for purchased services is also receiving partial support in the legislature at this time. This co-payment would be required for parents of children between age 3 and 17 years of age who live in the parent's home, receive services purchased through a regional center, and who are not eligible for Medi-Cal. The proposed Assembly Bill for this measure states that it would

institute a sliding fee scale, would take into account a family's ability to pay based upon adjusted gross income, would be adjusted according to family size, and also adjusted for families with more than one child with a developmental disability.

- An increase in the maximum staffing ratio for regional centers has been proposed as another way to cut funds. In other words, HRC Counselors and service coordinators throughout the state would be required to carry larger caseloads.
- Proposed reductions to MediCal rates, and elimination of certain MediCal benefits have thus far been opposed by both the Assembly and the Senate.
- Habilitation Services, currently being provided for many adults with developmental disabilities, will move from the Department of Rehabilitation to the regional centers. This change has been signed into law and will become effective in July of next year, 2004, to allow time for the transition to occur. This change will result in a savings to the state through a reduction of staff at the Dept. of Rehabilitation. It does not propose to give any staff positions to the regional centers to manage this program.

The ultimate outcome for all of the above proposals remains uncertain at this time, and legislators may still change their positions in relation to the overall budget situation. We will keep our community informed of changes to our budget, and how these changes will affect services, when they becomes known. Once again, we may need to call upon you to voice your concerns to our elected officials if a delay in passing the budget places our clients and programs in jeopardy. Together we will do all that we can to advocate for the best possible outcome for our clients and families. Thank you again for your continued support.

To be kept informed of major developments, and what you can do to help, join the HRC Email Network. Send an email to Nancy@hddf.com and ask to be added to the network mailing list.

ASSISTING YOUR CHILD TO BE SUCCESSFUL SOCIALLY

When describing her son's behavior during a recent birthday party, Norma Rodriguez expressed what many parents of children with special needs feel...“my child doesn't know how to interact with the other children.” Like Norma, many parents want to help guide their child to become successful socially, but sometimes they just don't understand how. Harbor Regional Center is offering a new training opportunity to parents to assist their child to learn the skills they need in social situations. The training is for parents who have a child, with a developmental disability, from the ages of six through adolescence, and is being conducted by HRC's service partner, Family Behavioral Services (FBS).

The *Social Skills Training Class for Parents* addresses what social skills are, and most importantly, how parents can teach their child these crucial skills. The class offers plenty of examples, real life situations, and group exercises that make learning fun. Each parent, if they desire, is given opportunities to speak about their particular concerns and work through them with the class.

“Preparing my child for the social situation, and the social situation for my child, is probably the most important thing I have learned,” states Norma Rodriguez. Many children with developmental disabilities are better visual learners and may not understand verbal instructions such as, “we are going to Grandma's, so you need to behave.” Using a social script, a series of pictures or drawings that tell a story, while showing a child what their behaviors should be, is one way of teaching your child social skills. In class, each parent learns how to put together these simple “books” to prepare their child for an activity, or to teach the appropriate social behaviors that child needs to focus on. Norma now prepares her son by using a social script, speaking to him ahead of time about the social sit-

uation he will be in, as well as guiding him once they arrive. For example, at a recent gathering, Norma joined in with the kids, demonstrating to her son how to interact appropriately, until he felt comfortable and began participating.

Ramon Gonzales discovered that it is important to be flexible with your child. His son can become frustrated in social situations, so this father wanted to know how he could prevent inappropriate behaviors from happening. To circumvent those behaviors, Ramon learned to consider his child's needs and feelings; in other words, knowing what causes the frustration, and consequently, the behaviors. When planning an activity for his child, Ramon now assesses such variables as the length of the activity, whether there will be a small or large group of people, and if there is a place for his son to have quiet time. Daniel Adatto, FBS Behavior Interventionist,

suggests easy solutions when planning something as simple as a trip to a restaurant. For instance, bringing some food so your child can have something to eat while waiting, or taking small walking breaks can make the restaurant experience better for you and your child. When other children are invited to your home, have planned activities for the kids, and acknowledge your child's threshold by watching the length of time the kids will be together. If you have been invited somewhere, bring your child's favorite toy or video. Preparation is the key for your child to have successful social opportunities.

For more information on the Social Skills Training Class for Parents, offered by Harbor Regional Center, please contact your HRC counselor.



Parents in the Social Skills Training Class discuss the use of the social script book.

THE HRC PARENT MENTOR PROGRAM ALLOWS YOU TO GET SUPPORT AND SUPPORT OTHERS

Eighteen months ago, Jodie Ryan had her first child. Her beautiful daughter, Delaney was diagnosed with Down Syndrome. Jodie immediately wanted information and someone to talk to who



Jodie Ryan and Delaney visit the HRC Resource Center to obtain information

might understand what she was experiencing. At that time, Jodie attended a support group but found it hard to find someone to speak to on a one-to-one basis. The Harbor Regional Center Parent

Mentor Program gives that one-to-one support for parents or other family members. Jodie is now a HRC parent mentor and is happy to help other HRC parents who find themselves in need of this special kind of support system.

When Tina Clements gave birth to her son, there were problems from the beginning. He had tremendous medical issues and needed a "trach," feeding tube, and had to be suctioned every few hours. Feeling alone and overwhelmed, Tina reached out for extra support from the HRC Parent Mentor Program. Her son was just six weeks old when she met the two people that became her Parent Mentors. They helped her through all the ups and downs she experienced with her son. For Tina, just having someone care and listen was a tremendous help. She

also became a parent mentor, even though her son passed away. According to Tina, "husbands don't always deal with the emotions that come with a diagnoses in the same way as you might, and friends and family might not know what to do or say, but a Parent Mentor has been in a similar situation and gives you an understanding that you might not get from others."

The HRC Parent Mentor Program is a valuable program, to both the parent who utilizes a mentor, and to the mentors themselves. Jodie Ryan took the Parent Mentor training class last October. During the class, participants learn how to become active listeners and who to call if you need additional support. There are organized notebooks, examples of possible scenarios, and an easy chart to assist you to keep track of referrals. Jodie feels that the Parent Mentor Program is an important program, that assists parents to get through the emotions and questions they may have when their child is first diagnosed. The support and information offered by a Parent Mentor can be through a telephone call or repeated visits but is always geared towards what the parent or family needs and feels comfortable with.

A Parent Mentor is valuable at many different stages in your child's life. For example, if your child is going into a new school program, high school, or from school to work, a Parent Mentor can give you the support and information you might need during these new stages of development. The Parent Mentor Program was used during different times of her son's development and when her son passed away, the Parent Mentor Program was a special gift to Tina and her family.

If you would like to support other parents in situations similar to your own, there will be a Parent Mentor Training Class on October 8, 2003 to introduce you to the Parent Mentor Program at Harbor Regional Center. Fathers are welcome too! We will go over the responsibilities inherent in volunteering and

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*HRC Team Makes Visits to Legislators
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doing our best to provide input, which we hope will guide our legislators in their difficult decisions. All of these team members helped us to put information about services and funding into a real life, local community perspective. We wish to thank them for their time and efforts.

Noah, Jayde, and Jerome Academia
HRC Client and family

Phillip Appelby
Past Board member, HOPE

Kristine Engels
Life Steps Foundation, HRC Board Member and Service Provider Advisory Committee Chairperson

William Frea, Ph.D.
Autism Spectrum Therapies

Pha Prum
HRC Client Advisory Committee

John Rea
Parent, HRC Board Member

Annette Ross
HRC Parent, HRC Board Planning Committee

Rita Teodoro
HRC Client Advisory Committee

Harry Van Loon
ARC Long Beach, HRC Service Provider Advisory Committee

Patricia Del Monico
HRC Executive Director

Colleen Mock
HRC Director of Community Services

Nancy Spiegel
HRC Director of Information and Development

Thank you to our legislators and their staff, for their valuable time, warm reception, and thoughtful discussions of the issues of concern to people with developmental disabilities:

Senator Debra Bown

Senator Betty Karnette

Assemblymember Rudy Bermudez

Assemblymember Alan Lowenthal

Assemblymember George Nakano

Assemblymember Jenny Oropeza

*The HRC Parent Mentor Program Allows
You to Get Support and Support Others
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offering peer support, and cover numerous other topics such as active listening skills, confidentiality and HRC workplace policies. We will provide a volunteer application form, set up a private interview, and help you determine which strengths you want to emphasize. Your expertise may be just what makes the difference for a new HRC parent.

If you would like to be assigned a Parent Mentor to talk to or would like more information about the class, please contact the HRC Resource Center at (310) 543-0691.



Besides being a Parent Mentor, Tina Clements volunteers her time at the HRC Resource Center.

HRC'S DENTAL COORDINATOR KEEPS CLIENTS SMILING

Learning how to brush your teeth effectively is just one of the lessons that Elsie Powell learns from Dental Hygienist, Jennifer Van Diest.



The clients from the Maidstone home learn about proper nutrition to help keep their teeth strong and healthy.

For many HRC clients, dental treatment can be hard to find, expensive because of additional costs such as anesthesia, and very complicated. For the dentist who cares for people with special needs, there can be added challenges including obtaining consent, talking about follow-up care with the patient and caregivers, and accessing health history information.

Last year, HRC added the position of Dental Coordinator, made possible by a grant awarded to the University of the Pacific, School of Dentistry, through the California Endowment. Marcey Brabender is HRC's Dental Coordinator. She has been hard at work developing resources including a list of dentists who are experienced in working with our clients, promoting oral health for people with developmental disabilities, and acting as the liaison between HRC clients, dental professionals, and other agencies.

Marcey's primary emphasis is the prevention of dental disease through education, which includes training our clients, and their caregivers, in proper brushing and flossing techniques. Currently, HRC's Dental Coordinator can be seen working at the ARC Adult Development Center, and

the Harbor Friendship Center, assisting HRC adult clients as they learn how to better manage their dental needs. She is helping more than 100 clients from these two programs, performing initial oral screenings, assessing their dental health, providing follow-up to assist both clients and their caregivers incorporate better preventive dentistry practices in their daily routines and making appropriate referrals for needed dental procedures.

One of the most exciting projects Marcey has coordinated is the "Adopt a Home" program. Working with Cerritos College, Dental Hygiene Program, the "Adopt a Home" program assigns three dental hygienists for every licensed home participating in the program. Currently, eight licensed homes are participating, with more than 30 clients benefiting from this innovative program. Once a month, the hygienists visit their assigned homes where they conduct oral screenings, instruct clients on how to brush and floss their teeth correctly, as well as assist them in obtaining and using adaptive equipment that makes brushing and flossing more efficient. Each hygienist works with a client on a one-to-one basis, spending as much time as needed with them. Clients report that they feel more comfortable with the training because they are in their own homes, using their own toothbrush or other equipment.

In Norwalk, at the Maidstone Home, Jennifer Van Diest has been working with Elsie Powell on proper flossing techniques. Elsie looks forward to working with Jennifer and although Elsie has good overall dental hygiene practices, she has learned some valuable lessons. She is now brushing her teeth longer, for a minimum of two minutes, including the roof of her mouth and tongue. The Adopt a Home program has also made a difference to the people working with our clients. The staff from the various homes receive support, training, and dental supplies. At the Maidstone Home, Francine Law not only has seen

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HRC's Dental Coordinator Keeps Clients Smiling (continued from page 6)

a difference with the clients she works with, but in her own increased knowledge of oral health practices.

The HRC Dental Coordinator position has been extended for another year. Through the generosity of the California Endowment, Marcey can continue to assist HRC clients to have a healthier smile.



HRC's Dental Coordinator, Marcey Brabender works with Glen Woodruff and his caregivers on proper dental care.

IMPORTANT CHANGES IN ACCESS PARATRANSIT SERVICES

Access Paratransit is a shared-ride, curb-to-curb service for Los Angeles County, available for elderly or disabled riders. Eligibility for Access services is based not only on the presence of a certain disability, diagnosis or age, but also upon a client's ability to use accessible bus service in Los Angeles County. Many HRC clients use Access services to travel to doctor appointments or when taking care of other daily needs. Beginning July 1, 2003, Access will be initiating changes to become more responsive and efficient, addressing both client needs and budgetary issues.

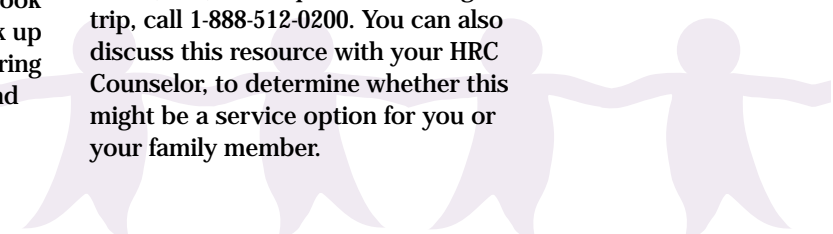
There are three major changes:

- Reservations will be taken on a "Next Day" basis. Next Day reservations will be taken from 6:00 a.m. until 10:00 p.m., for the following day. This means, if HRC client Amy needs a ride to the doctor at 11:30 a.m. on the following day, she can call anytime during the designated reservation hours and book her ride. Clients will be able to book up to six one-way trips for any time during the following day. By adding staff and telephone lines during reservation hours, Access hopes to reduce the wait-time many clients encounter while reserving their rides.

- "Same Day" trips will be provided, at a greatly reduced level, and on a space available basis. Riders who wait to schedule trips until the day they wish to travel may not be able to obtain a ride because of the reduced space on Same Day trips.
- The "Steady Service" trips will continue, but will be renamed "Standing Order" trips. Standing Order is used by riders who make repeated trips, for instance, to work or to school. With the implementation of the new policies, Standing Order trips will be available to more riders.

Access suggests that when planning a trip, remember that Access Paratransit is a shared ride service, and there can be other passenger pick-ups and drop-offs along the way. When making a reservation, riders should generally allow 60 minutes for trips less than 20 miles, and 90 minutes for trips more than 20 miles.

You can receive more information about the changes in Access services or apply for eligibility by calling Access Customer Service at 1-800-827-0829 or 1-800-827-1359 (TDD). To request a Standing Order trip, call 1-888-512-0200. You can also discuss this resource with your HRC Counselor, to determine whether this might be a service option for you or your family member.



Client focus

A PASSION FOR GIVING BACK TO OTHERS

If you were watching the L.A. Marathon, you might have noticed one especially inspirational participant. Jeri Formby can't run the route, but walks with assistance as far as she can, then with the help of her sister Lisa, finishes the route in her wheelchair. This determined individual loves participating and has as much fun and takes it as seriously as anybody else. For nine years, Jeri and her sister, Lisa, have participated in the L.A. Marathon, making many friends along the way while raising money for charity.

With her sister, Lisa, Jeri Formby is all smiles at the start of this years L.A. Marathon.



This passion for giving back to others was first inspired by Jeri's parents. "I received so much support and assistance for both Jeri and her brother who also has a disability," recalls Patricia Harsh, Jeri's mother, "and as a family we felt that we should give back to others because of the tremendous help we had received." For many years, the whole family would participate in the March of Dimes WalkAmerica. When Jeri was five and seven years old, she was chosen the Southern California March of Dimes Poster Child. According to her mother, Jeri loves to participated in activities that assist others. To raise money for their favorite charities, Jeri and her mother make crafts and baked items to sell at different fundraisers. Besides the LA Marathon, Jeri contributes time and money to Easter Seals, Saint Jude, and the March of Dimes. Jeri is persistent and was able to gather over \$2,000 in sponsorships from her friends and neighbors for the LA Marathon, which was then donated to the AbilityFirst program.

Life for Jeri Formby began with challenges. She was born with Cerebral Palsy and has endured six major surgeries. Through it all, Jeri remained a model patient, never complaining and always staying positive. When Jeri is at home, she walks with the aid of a walker for short periods but primarily relies on a wheelchair. Her biggest challenges have not been the pain or surgeries, but her inability to speak. A few years ago, Jeri began using an augmented communication device which allows her to type in the words or phrases she wants to say. The communication device assists Jeri

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*A Passion for Giving Back to Others Smiling
(continued from page 8)*

to better communicate with the world around her, and as she jokes, allows her to better solicit all those contributions.

Jeri lives with her parents and loves sports, frequently watching Laker games or car racing. The highlight of her day is helping her mother care for her young niece and nephew. Jeri attends the AbilityFirst Adult Development Center where her favorite jobs are the postal

duties, including putting labels on envelopes, folding, and stamping the mail. "Jeri refuses to quit and has quite the stubborn streak," relates her mother. "These qualities have brought her much farther in life than the doctors imagined when she was born." Jeri has a tremendous attitude and will be your friend for life. Jeri feels lucky for so many things in her life, including her family and her friends, and wants to give thanks by continuing her altruistic work for many more years.

RECOGNIZING EXTRA EFFORT!

Would you like to recognize someone at Harbor Regional Center for their efforts?

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, through their actions, 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 Kathryns@hddf.com**

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.

HOPE's Annual Fundraising Event Supporting Housing Opportunities for HRC Adult Clients

HOPE (Home Ownership for Personal Empowerment) celebrated its seventh annual fund raising dinner and auction at the Museum of Latin American Art in

Long Beach on Saturday, May 17, 2003. The one hundred and fifty guests who attended were surrounded by palm trees, beautiful hand-painted centerpieces and a spectacular variety of South American, Caribbean, and Central American art pieces. Phil Brock of Studio Talent Group served as Master of Ceremonies and Auctioneer. Hollywood Actor and Producer, Tom Hallick and the honorable Richard Leopold, HOPE Board Member excelled as the Live Auctioneers.

The evening celebrated the individuals and corporations whose time and contributions have assisted HOPE to continue to offer affordable housing to adults with developmental disabilities. There was fierce bidding on the fabulous prizes at both the live and silent auction and one lucky raffle winner received the wonderful dream vacation for two at the Royal Kona Resort at Kailua-Kona on the Big Island of Hawaii. The evening was a huge success and the event made over \$25,000 for HOPE.

HOPE would like to thank all of our volunteers for their time and talents in making this event such a success. Volunteers that deserve special mention are Leslie Tillmann and Mary Doyle for the beautiful centerpieces and HOPE Board Members Patricia Rahmann, Wayne Anthony, Tom

Bramble, Robert Bethel, Richard Leopold, Ann Menard, Janet Thomas, Sandy Throop and Rolf Tillmann. Volunteers Sherry Leopold and Lynne Stahl were indispensable at soliciting auction items. A special thanks to all the HRC staff volunteers whose contribution was so important to the event's success.

HOPE is a nonprofit organization that currently owns 28 properties rented to more than 76 Harbor Regional Center adult clients. If you would like to contribute to HOPE or need more information about the program, contact Jennifer Byram at (310) 543-0635.

Staff Honored at Luncheon

For HRC clients who live in licensed care homes, the people that may have the biggest impact in their lives are the direct care staff who offer daily training and support. Harbor Regional Center, with the assistance of the Direct Support Professional Planning Committee, consisting of owners of licensed care homes, planned the First Annual Direct Care Staff Appreciation Banquet to acknowledge and celebrate the importance of direct care staff. This wonderful event was funded entirely from donations from the committee, and the community, and was held at the Reef Restaurant in Long Beach on May 14,

2003. There was a Hawaiian theme complete with Hawaiian music and dancers and buffet. The highlight of the event was the drawing to raffle the door prizes including hair care certificates, gift certificates to wonderful local stores and restaurants, and even a television. HRC Executive Director Pat Del Monico gave the welcome address and thanked all of the direct care staff for all their hard work and important contributions. The event, attended by more than 200 people, was a huge success.



KNOW WHAT TO EXPECT ONCE YOUR CHILD LEAVES SCHOOL

Your child is in high school, one step closer to leaving the familiar daily routine of school for an unfamiliar world. For parents who want to become more knowledgeable about what to expect as their child prepares to exit the school program, Harbor Regional Center provides a unique training opportunity; *Getting There: Exploring New Paths: The First Steps in Transition from Adolescence to Adulthood*.

Maggie Rose-Van Dyke knows the uncertainty a parent can feel. Her daughter, Michelle, is currently a Freshman at Redondo Union High School. And though Michelle is only fourteen years old, Maggie felt very concerned about what Michelle will be doing when she turns eighteen and is no longer in school. Maggie remembers attending her daughter's first Individual Transition Plan (ITP) meeting at school, and not knowing what to expect. The need for more information led Maggie to this education opportunity.

Maggie hoped to gain specific information concerning Social Security benefits and the choices in living arrangements that might be available for her daughter, so she enrolled in this HRC course. What she found was valuable information from the different choices in vocational or educational programs, to the types of services and supports available from different community organizations.

Parents learn how they can assist their child to decide what they might want to do with their life. They also discover how to best work with the school district and your HRC counselor, to access the programs, services or supports your child will need to be successful.



The class offers information that helps you and your child achieve his or her chosen future, and make the transition from school to the adult world a smoother one. Maggie is glad she attended the workshop. She now feels more prepared for the future. As she relates, "I felt I needed to start now to prepare for Michelle's future. The high school years will fly by and I didn't want to wonder what we should do next."

Maggie Rose-Van Dyke and her daughter Michelle have reason to smile because they now know what to expect when Michelle is no longer attending school.

Getting There: Exploring New Paths: The First Steps in Transition from Adolescence to Adulthood will be offered on Thursday, October 16, 2003. To obtain more information about this or other training opportunities, access the HRC Training & Events Catalog which is mailed twice a year or is available at the HRC Resource Center, from your HRC counselor, or online at www.HarborRC.org.

HRC STAFF BENEFIT FROM EDUCATIONAL OPPORTUNITIES

Dr. Ira Lott speaks about recognizing the signs of dementia and Alzheimer's Disease in adult clients.



Harbor Regional Center staff and others who work with our clients are given many opportunities for additional training and education throughout the year. Recently, HRC sponsored two important trainings that dealt with Alzheimer's Disease, and Working with the Courts. These workshops gave participants information that can assist them to better meet the needs of our clients.

Working More Effectively with a Client Diagnosed with Alzheimer's Disease

On February 25, 2003, Dr. Ira Lott, M.D., Director of both the Down Syndrome Project, and the Division of Child Neurology at UCI Medical Center, gave a presentation from

his educational and outreach project, *Management of Individuals with Dementia and Developmental Disabilities: Guidelines for Health Care Personnel and Caretakers*. Sponsored by a grant from the California Department of Health Services, Dr. Lott has adapted the approaches and

techniques used for Alzheimer patients and geared them especially for persons with developmental disabilities.

To effectively deal with a diagnosis of Alzheimer's Disease and Dementia in a person with a developmental disability, the use of an assessment tool that gives an accurate measure of mental functioning, and the client's ability to carry out daily living skills is very important. Dr. Lott also recommends that medical records be organized and up-to-date, and caretakers become knowledgeable about specific medical concerns such as seizures and the behavior disorders that are often associated with dementia.

To better facilitate treatment for a client with Alzheimer's and Dementia, Dr. Lott recommends a number of guidelines including the following:

- Develop a partnership between the patient's primary physician and caretaker to provide regular health check maintenance, and to monitor therapies for dementia.
- Understand the medical review process such as medication assessments, monitoring of the disease progression, and the use of dementia medications.
- Provide a predictable routine for daily activities, explain all activities before performing them, and simplify tasks to the appropriate functional level of the client.
- Allow the client to dress in their own clothing but not lounge around in pajamas all day long.
- Reduce excess stimulation, crowded conditions, and secure a safe environment.

Working with the Courts

HRC Counselors are sometimes called upon to engage in complex advocacy for clients involved with criminal, mental health or family courts. To do so effectively, our counselors – who generally do not come from a legal background – must develop a basic understanding of the court system. To address these issues, HRC periodically provides trainings to assist staff to better work with the various court systems.

On April 15, 2003, George Bird, Attorney at Law, a certified criminal law specialist, addressed the role of the counselor in working with the courts. The presentation included important issues such as who's who in court, what are the criminal court and the other types of courts, and what are the specific functions of all these courts. He helped staff understand the different categories of criminal offenses, and how to best work with their clients and court personnel. This training, attended by over seventy-five counselors from many different regional centers, was very informational.

George Bird, Attorney at Law gives HRC staff and others valuable information on how to effectively work with the court system



HRC IN THE COMMUNITY

Resource Fair For Adult Clients and Their Parents

Harbor Regional Center, and the Long Beach Unified School District, Vocational Education Division recently collaborated on an adult services resource fair. The fair, held on April 11, 2003, featured over thirty vendors from many adult programs including adult day programs, supported employment services, Social Security, adult drop-in centers and much more. Parents and other caregivers gathered information about the various programs and were able to ask questions about the programs. While their parents were investigating programs, the adults clients had fun dancing the night away.

HRC Resource Center Gets the Word Out on Car Safety & Booster Seats

Though approved car safety or booster seats have shown to greatly reduce severity of injury and prevent death for children in motor vehicle crashes, many parents may not know how to correctly secure the child safety or booster seats, or that their child should be riding in one. To get the word out to as many parents and caregivers as possible, the HRC Resource Center recently participated in several community resource fairs, where they distributed valuable information concerning car safety and booster seats.

HRC Resource Center Staff were participants on May 3, 2003, at the Miller Children's Hospital *Celebrating Families Safety Fair* in Long Beach, and on May 10, 2003, at the *Parent Success Conference & Resource Fair* in Manhattan Beach. At both locations, Easter Seals of Southern California displayed a variety of samples of car seats made especially to accommodate special needs children so parents were able to see what is available.

(above) Working with Miller's Children's Hospital Celebrating Families Safety Fair, the HRC Resource Center's Pha Prum measures a child's height to see whether he should use a car seat, booster seat or just a seat belt as the proper car restraint.

(right) Parents participating in the Adult Services Resource Fair learn a little more about adult day activities.



Issues of Harbor Happenings can be found at the Harbor Regional Center World Wide Web site at www.harborrc.org



Designing Mobility

Custom Wheelchairs and Seating

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resource center

WHAT'S NEW AT THE RESOURCE CENTER ?

*By Tina Clements
HRC Parent and HRC Resource
Center Volunteer*

The Harbor Regional Center Resource Center is the place to go for information and support. There are literally thousands of books, videos, magazines, and other wonderful sources of information and inspiration. This month, the HRC Resource Center focuses on books that use humor and are inspirational. The following reading materials are very uplifting and great reading for HRC clients, family members, or anyone who just needs a laugh or to be inspired.

Bitter or Better *by Paul Haigazian*

The author tells his story of living with a diagnosis which caused severe physical and mental disabilities. Paul goes on to have a bright future which he credits to the philosophy that it is not what a person has, but what he does with it that counts. This book provides the reader with encouragement to persevere through tough times.

From the Heart: On Being the Mother of a Child with Special Needs *by D. B. Marsh*

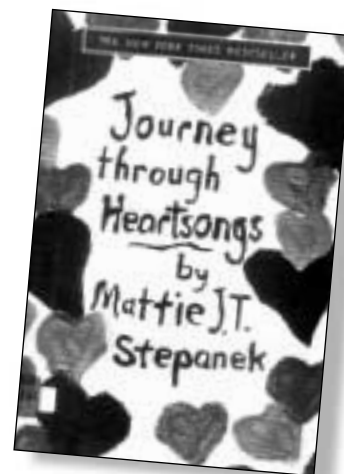
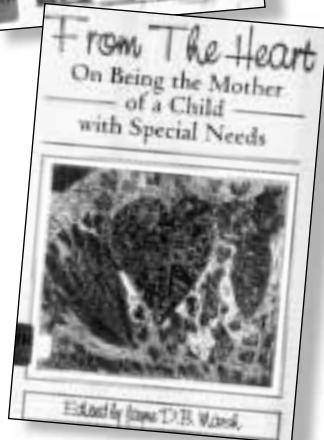
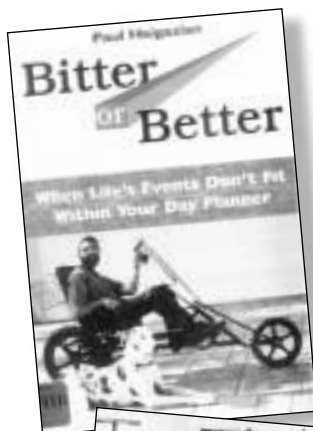
Through touching stories and narratives, nine mothers explore the intense, sometimes painful emotional terrain of raising a child with special needs. There are stories from mothers of children with Autism, Down syndrome, Cerebral Palsy, ADD, and other multiple disabilities.

Stand, Walk, Run Free *by Constance Morgan*

This book describes a mother's account of the unrelenting tension that may be part of the impact of a disabled child on the family. It vividly illustrates the hidden factors in our culture that forced this young mother to reconstruct her life and in the process discover the one thing that will always bring her happiness. Compelling and supremely inspiring, this is the story of love that transcends all obstacles and demonstrates the indestructible power of the human spirit.

Journey through Heart Song *by Mattie J. T. Stepanek*

The author, who is also a child, writes movingly and courageously about life and death, love and loss, faith and hope, and innocence and joy. His struggle with a rare form of muscular dystrophy has given him wisdom and insight, well beyond his years. He reflects on his life in his award winning poetry.



AUDANDO A SU HIJO A SER SOCIALMENTE APROPIADO

Describiendo el comportamiento de su hijo en una reciente fiesta de cumpleaños, Norma expresó lo que muchos padres de niños con necesidades especiales sienten... “my hijo no sabe como actuar con otros niños.” Igual que Norma, muchos padres quisieran ayudar a sus hijos a ser aceptados socialmente, pero no saben como hacerlo. El Centro Regional Harbor esta ofreciendo una oportunidad de entrenamiento, para aquellos padres interesados en ayudar a sus hijos a aprender lo que necesiten en situaciones sociales. El entrenamiento es para padres que tengan un niño o niña con incapacidad de desarrollo, de seis años hasta la edad de la adolescencia, y las clases serán conducidas en coordinación con el Family Behavioral Services (FBS).

En estas clases para los padres, se emprende la tarea de lo que es obtener la habilidad social, y mas importante, cómo los padres pueden enseñar a sus hijos a adquirir dicha habilidad para ser adecuadamente social. En la clase se ofrecen suficientes ejemplos de la vida real y ejercicios en grupo que hacen que la clase sea mas divertida. Cada padre, si lo desea, puede compartir sus preocupaciones y observaciones y así facilitar lo que aprenden todos en la clase.

Los padres que han tomado el curso han expresado el gran beneficio que este conocimiento ha tenido en sus vidas. “Preparando a mi hijo a saber como comportarse socialmente es probablemente lo mas importante que he aprendido” dice Norma. La mayoría de los niños con incapacidad de desarrollo aprenden mas fácilmente de forma visual y tienen mas dificultad en comprender las instrucciones verbales como “vamos a casa de abuelita, a si que te tienes que portar bien.” El uso de una libreta/guión, con fotos o dibujos que dicen una historia, ayudan a los padres a enseñar cual debe ser el comportamiento del niño y facilita que su niño aprenda a actuar apropiadamente en situaciones sociales. En la clase los padres aprenderán como hacer estas libretas para preparar a su niño a aprender la conducta social que

su niño en las circunstancias que el mas lo necesite. Norma utiliza una libreta que ella ha preparado y habla con su niño antes de tiempo para prepararlo acerca de cual va a ser la situación, como también asistiendolo cuando lleguen al lugar. Por ejemplo, en una reciente reunión, Norma se mantuvo con el grupo de niños, demostrandole a su niño como actuar recíprocamente, hasta que el se sienta mas seguro de si mismo y empiece a participar por si solo.

El señor Ramón descubrió por si mismo que tiene que tener flexibilidad con su niño. Su niño puede sentirse frustrado y exhibir comportamientos inapropiados en situaciones sociales, así que el padre quería saber como prevenir el mal comportamiento. Para evitar problemas, Ramón aprendió a tomar en consideración las necesidades y sentimientos del niño; en otras palabras, averiguando que causa la frustración y consecuentemente el mal comportamiento. Cuando se esta planeando una actividad para el niño el se asesora si el niño va a estar con un grupo de personas pequeño o grande, y si va a haber un lugar donde el niño podrá tener un momento tranquilo de descanso. Daniel Adatto, Intervencionista del FBS, sugiere soluciones simples cuando se planea algo como un simple viaje a un restaurante. For ejemplo, llevar algo para el niño comer mientras durante la espera, o tomando una pequeña caminata puede hacer la experiencia de ir a un restaurante mejor para el niño y su familia. Cuando otros niños están invitados a su casa, tenga actividades ya planeadas para los niños y reconozca el umbral de su niño por medio de estar observando el periodo de tiempo que los niños van a estar juntos. Si ustedes son invitados a algún lugar, determine primero si van a haber otros niños, juguetes, videos u otras actividades para su niño, o si usted deber llevar algún objeto o planear alguna actividad que sea del agrado de su niño. La preparación es la llave para que su niño tenga oportunidades sociales positivas.

Estos han sido algunos de los ejemplos de los métodos que los padres pueden aprender para satisfacer las necesidades de su niño. Para mas información acerca de las clases de Entrenamiento de Habilidades Sociales para los Padres, pongase en contacto con su consejero del Centro Regional Harbor.

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BOARD MEETINGS

No Meeting in August
September 16, 2003 – 8:00 a.m.
October 21, 2003 – 6:30 p.m.
November 18, 2003 – 8:00 a.m.
No meeting in December

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 meetings are from 6:30 to 8:30 p.m.

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 B 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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