

THE OREGON CLARION

A Voice for Oregonians with developmental disabilities and their families

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The challenge of maintaining values

“Values are the core foundation, the mirror we look into to try to understand what is happening and what to do next,” says Laurie Powers, Co-Director of the Oregon Health & Science University Center on Self-Determination. “Values are in danger of being lost as guideposts.”

Powers is only one of many advocates, family members and professionals who are increasingly concerned about how to manage a service system with less and less financial resources, while, at the same time, honoring and implementing chosen values. Values such as choice, inclusion and self-determination—values this community has fought hard for over many years.

Bob Gettings is Executive Director of the National Association of State Directors of Developmental Disabilities

Services. “Values are what guide us in terms of public policy choices we make. I would be very fearful of a value free decision making policy.” Asked specifically about Oregon’s nationally known budget problems, he said from his office in Alexandria, Virginia, “Oregon’s situation, mirrored in other states, is very threatening. It is like trying to figure out in the middle of a tornado what the damages are. You know the situation is extremely dangerous. The consequences can’t be good. How bad, we don’t yet know.”

Laws guided by values

From babies to seniors with disabilities, the laws that govern disability policy are full of value statements. But, according to Kathryn Weit, Policy Analyst with the Oregon Council on Developmental

Disabilities, those values are not always clearly reflected in the administrative rules that guide service providers. “Statutory language is fine,” says Weit. “But without clearly stated values in administrative rules, we lose the spirit and context that should guide the delivery of services. Language identifying the guiding principles and values needs to be in every administrative rule as a constant reminder to everyone who uses the rule.”

For Diana Allen, Director of Early Intervention/Early Childhood Special Education at the Oregon Department of Education, values are at the core of her work. “Values, such as natural environments, are reflected in our law and administrative rules. That language is in every contract and subcontract.”

Allen acknowledges that

there is more to it than simply putting language into contracts. “As the budgets have tightened, programs are looking at service models and asking whether or not that model meets the values requirements. Contractors and subcontractors call me and say, ‘this is what the state is giving us to run a compliant program, and how do we do it on this amount of money?’ It is in these local programs where values and ideals are really tested. The staff believe in the values and ideals but they struggle everyday with how to implement them with shrinking or flat funded budgets.”

High expectations colliding with budget reality is very much on the mind of adult services’ administrators. Kathie Labadie is Manager of the In-Home Supports Section at the state office for Seniors

See VALUES on Page 6

Jim Staley—the man behind the lawsuit

Contrary to what many people think, the famous *Staley* lawsuit settlement is not named for famous mom and past president of The Arc US, Karen Staley, but for an equally distinguished advocate of the same name and from the same family, her son, Jim Staley.

Jim Staley is a named plaintiff in the celebrated class-action lawsuit, officially known as *Staley, et. al. v. Kitshaber*. For obvious reasons, the litigation is simply called “the *Staley* case”. Much written and talked about, it is the vehicle by which an entitlement to services became a reality for every eligible, adult Oregonian with a developmental disability.

Like all great events, this one has behind it an even greater personal story.

Jim Staley is 37 years old. Thanks to the settlement agreement that bears his name, he now lives in his own apartment in East Multnomah

County. “My home,” is how he describes it. Jim is not a wheelchair user but the entrances to his home are fully accessible. Jim Staley welcomes lots of people here to

his parents was among the guests. They were out of town. Like any 37-year-old single man, this made no difference to Jim. “My friends brought a Karaoke machine from the

ing room. “It was fun,” he says.

During the interview for this article, a visitor asks, “May I use the phone?” In a room full of family and staff, only one voice answers. “Yes,” says Jim Staley with authority.

“We signed Jim up for the
See STALEY on Page 5



Jim and Karen in Jim’s kitchen

his home, on his terms.

On his most recent birthday, sixty people came to celebrate with him. Neither of

bar,” he says with assistance from his mother. Jim’s large frame is draped nonchalantly over an easy chair in his liv-

Settlement agreement signed

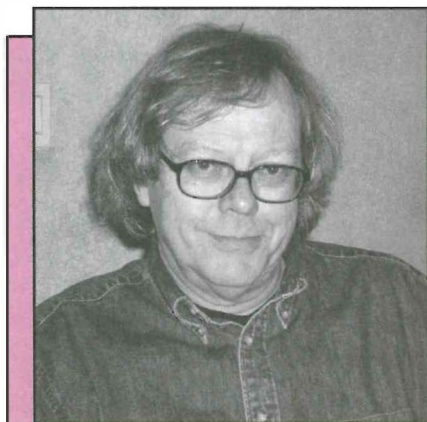
On September 22, Governor Kulongoski signed the amended settlement agreement for the Staley lawsuit. The agreement was negotiated between lawyers representing the state and the plaintiffs in the case. The signature means that brokered services will continue without interruption.

For details of the amended agreement, see “Ask OAC” on page 4.

Research for this issue of *The Oregon Clarion* gave me an opportunity to speak with dozens of thoughtful people. Although everyone agrees that values are under siege, there is a great difference of opinion as to what this means now and in the future.

Advocates and administrators consistently referenced the French word *ennui*, meaning a combination of tediousness and boredom. "Advocates are aging," one national figure told me. "We are sick and tired of fighting the same battles over and over again." Others expressed a fear that once administrators and parents have completed the process of protecting already slim budgets, they simply have little energy left. "We get through one day at a time," several parent advocates told me.

If, indeed, *ennui* is a problem, then what can we expect in the way of relief? And here it is im-



Editor's Corner

Michael T. Bailey

possible not to return to state and federal financial issues. By now everyone is familiar with Oregon's budget problems. Can we hope to look to the federal government for some rescue, some relief?

Federal budget numbers don't give us any reason to hope. In April 2001 the Bush Administra-

tion announced that fiscal year 2003, the one we are in now, would have a budget surplus of \$334 billion. In fact, the present federal budget contains a \$455 billion deficit. That is a budget swing of \$789 billion in two years. Over this decade the administration is now projecting a federal deficit of roughly \$9 trillion.

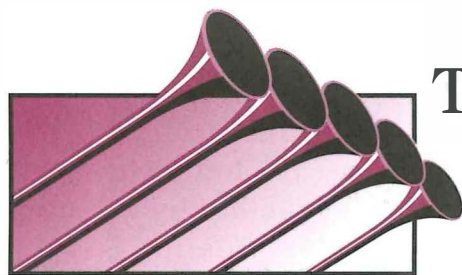
Given those realities it seems unlikely that our problems will be addressed by federal spending.

The legislature passed a small tax increase that protects some of our programs. The ink was hardly dry when an initiative

petition began circulating to ask voters to repeal the increase. We enter this new budget cycle with as many questions as answers.

If crisis is opportunity than we all need to renew our faith in the values we profess. Inclusion begins at home. It extends to our actions to one another. It is time to look into our own hearts and see if we are living up to the values we say we want in our programs.

We are in for some hard times. Let's deal with what we can control. Our own examples will ultimately matter more than the whims of the political process.



THE OREGON CLARION

A Voice for Oregonians with developmental disabilities and their families

clarion (klar'-e-on) n. 1. an ancient trumpet and the brilliantly clear sound it makes. 2. a call to action. 3. a voice for Oregonians with developmental disabilities and their families.

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Send your submissions to the above address c/o Michael Bailey, Editor, The Oregon Clarion.

DEADLINE FOR THE NEXT ISSUE: NOVEMBER 15, 2003

Council selects new director

The Oregon Council on Developmental Disabilities has selected Bill Lynch as its new executive director. He served as interim director of the Council since the departure of Janna Starr, who resigned last March to accept a new position in Washington D.C. The Council conducted a national search that culminated in the selection of Lynch. "We are delighted to have Bill accept this position and look forward to a long and productive future with him," says Cynthia Owens, Council Chair.

Lynch had been the planning and communications coordinator for the Council since 1994. Prior to that he was a research assistant for the Specialized Training Program at the University of Oregon, where he worked on projects related to the employment of people with severe developmental disabilities. He got first job in developmental disabilities in 1981 when he joined the staff of The Arc of Oregon.

"The Oregon Council has a strong national reputation," says Lynch, "and has had a big hand in the advocacy achievements in this state during the past thirty years. I look forward to working with all our partners and collaborators to continue this good work."

LETTERS TO THE EDITOR

Dear Clarion,

Last November a presentation was made about www.housingconnections.org to a meeting of the Housing Advisory Group in Washington County. That information was reiterated at our Families for Independent Living board meeting which led to a pair of placements in subsidized low income housing. One young woman with developmental delay had waiting 12 years to move out of her family's home. The other young woman had waited at least 8 years in the same circumstance. This website makes finding supported housing extraordinarily easy with the parameters of the users choice.

Gordon Teifel
Families for Independent Living
Aloha, OR

Dear Clarion,

I really enjoyed the July issue of the Oregon Clarion. I had the

same experience with my daughter's medications as Andy Owens had with his. My carrier had their computer coded to say that they weren't going to cover my daughter's prescription, but it wasn't the truth. They would cover it if you broke the pill in half, something we have been doing for years. The prescription is for fifteen tablets for a thirty-day supply.

So the insurance company pricked up because of the possible misrepresentation of their benefits. I filed a complaint because, as I told them, I'm concerned that people who aren't nurses won't "get it" and will miss important medicine they think is no longer covered.

I had to make a stink, but they actually changed the computer program that day. It took hours on the phone, just like in Andy's case.

Betty Hale
Portland, OR

Challenging schlock radio in Oregon: an advocacy success

By HOWARD KLINK
PORTLAND

Listen up schlock radio fans! For what may be the first time in the nation, a community has stood up to a major media corporation and said, "Your programming is abusive and disrespectful of people with disabilities and we're not going to take it anymore!"

Portland's FM station "Jammin '95 Morning Playhouse" program featured a man with developmental disabilities named J.V. His role was to be humiliated on air for his inability to perform tasks. The radio program bought J.V. a lap dance for his birthday and put pictures of him receiving it on their web site with the caption "This guy hasn't been laid for 20 years."

Then came a woman with developmental disabilities who was approached for an "interview" while waiting for her bus. On live radio she was referred to as the "fattest, ugliest woman" the reporter had ever seen and made the subject of "retard" jokes.

Station manager Tim McNamara, after being told of these incidents, said "I've taken enough crap over the last 3 days for making fun of the mentally disturbed, I'm going to stick to making fun of midgets and hair lips."

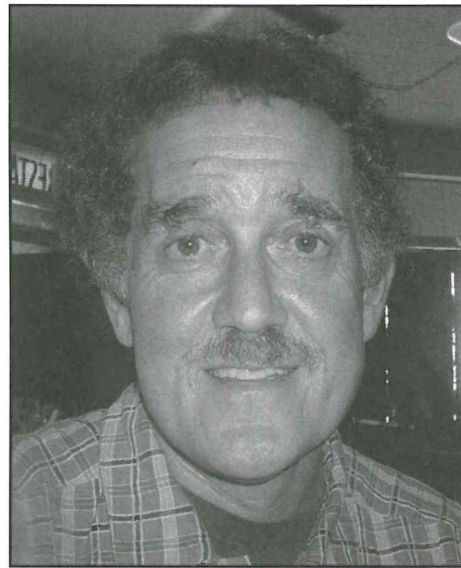
After receiving calls and letters from the advocacy community, The Shane Company jewelers terminated their advertising contract with the station resulting in the loss of \$100,000 in advertising revenue.

But even after the revenue loss, the station introduced "Special Jen" as a stripper at a sponsored event. Responding to complaints that she appeared to be a person with a developmental disability the station responded, "She's not retarded. She's a drug addict."

The station responded to only a few of the hundreds of calls and e-mails they received and did meet with a group of advocates. They admitted they were an "equal opportunity offender."

The gist of their defense was that "It's intended to be humor, we make fun of everybody," and "If you don't like it, don't listen."

At the same time, they admitted that there were lines they would not cross such as the on air use of certain racial slurs. Why target people with disabili-



Howard Klink

ties? They had simply not expected a powerful community to react with rage. The bottom line is that they have the right to air this trash and our community has the right and the responsibility to protest.

Like racism, this type of abuse is driven by ignorance and bias. By treating people with disabilities with disrespect, it sets the stage for humiliation of children in school and verbal and physical abuse in the community. It has the same effect as racial, gender, religious or age-based discrimination. It creates the potential for hate crimes.

The station is owned by Paul Allen. Until recently, Portland Trailblazer General Manager Bob Whitsett has supervised the station.

There are over 15,000 adults and children with developmental disabilities in Oregon. People live in their own homes and in the community. People fully participate in the community. Many people are former residents of institutions like Fairview and have worked hard to create meaningful, productive lives.

People in our community have families, friends and neighbors who support them. So it is no surprise that programming like this outraged not just people with developmental disabilities but people from the community at large and other media outlets.

The community response was an example of a near perfect organizing strategy. We employed a large volume phone and e-mail campaign and, significantly, persuaded a major sponsor to termi-

nate their contract. Both *The Willamette Week* and *The Oregonian* newspapers picked up the story and published highly critical stories of their own. This was followed with a monitoring network to listen and report on new programming. The result is that staff were disciplined, apologies were made and the programming stopped.

This truly demonstrates the power of organizing and advocacy.

Japanese activists sue: *Matsuoka vs. Hino City*

In October 2002 People First of Japan filed the first ever de-institutionalization lawsuit in their country's history. "Disability rights activism by persons with developmental disabilities is thriving in Japan," says Lynnae Rutledge of Portland.

Rutledge spent five weeks in the Tokyo region observing disability policy and activism.

The named plaintiff in the suit is Mr. Matsuoka, a young man with a developmental disability, who was institutionalized, against his will, in 1995. His lawsuit seeks damages from Hino City, the political entity that sent him to the institution. The suit contends that failure to allow him to live in his community with necessary supports, violates both the Japanese Constitution and the 1975 United Nations Declaration on the Rights of Disabled Persons. In related litigation, Matsuoka seeks financial compensation from the corporation

operating the institution and the bank that financed it.

Although the Japanese constitution guarantees the dignity and equality of individuals under the law, "persons with disabilities continue to be subjected to serious discrimination and violations of human rights in every aspect of everyday life due to deeply rooted prejudice and lack of understanding," says Rutledge.

The lawsuit was filed to coincide with the Disabled Peoples' International World Assembly, which brought 2,500 people from around the world to the city of Sapporo. "News of the lawsuit was widely covered in the Japanese press," notes Rutledge. "One of the case's purposes is public education."

The case is still pending, but according to Rutledge "it marks the beginning of an advocacy effort that is being watched around the world."



Photo courtesy of Robbie Alvord

Travis Streets of Dallas smiles after completing his article for The People First Connection: The Voice of Self Advocacy in Oregon. Travis was one of the participants in a Writer's Workshop sponsored by Self Advocates As Leaders on July 23 in Monmouth. Groups that would like to host a writer's workshop can call Self Advocates As Leaders, 503-232-9154 ext. 133.

LETTERS TO THE EDITOR CONTINUED

Dear Clarion,

I assure you that all the letters and e-mails in the world will not get this group of politicians we now have in Salem to do anything. I hear only silence. The true Oregonian may care what happens to disabled people but that's about all. I am very disappointed in how low Oregonians

have sunk.

We have lost many of our best teachers and doctors and now we will see our best caregivers move away to other states. This void will take years to fill. Truly the people of Oregon are a sick lot as reflected by their leaders in Salem.

Pat Ireton
Pacific City, OR

Value based decisions: balancing budgets and ideals

In August, Mary Lee Fay, Administrator of the state Office of Home and Community Supports, Seniors and People with Disabilities, sat down with The Oregon Clarion to discuss choice and values in Oregon's service system.

What happens to personal choice when the cost of in-home services far exceeds the cost of the same care in a nursing home?

The way the laws and rules read, for seniors and people with disabilities, the cost of care is a critical factor. But it is not the only factor. Cost has to be considered within the context of promoting individual choice and dignity. There is a threshold that includes cost but also includes safety and choice. It is not true to say that when costs are driven up people will not be able to stay home.

There are a couple of concerns that people have here. One is the nursing home tax. People worry that it puts money back into nursing homes and thereby perpetuates and strengthens them as an option. That tax is imposed on all nursing homes. It cannot exceed 6% of their revenue. They pay it to the state, which turns around and gets a Medicaid match with those dollars. People see nursing homes as a place where revenue goes.

The other worry people have is the home care worker issue. Increased pay and benefits for those workers increases the cost. People worry that this means that foster care will be cheaper than in-home care and will therefore be a preferred

method. The answer is that we want to promote choices in a least restrictive environment. We are not directing the field to use cost as their ultimate driver. It is merely one factor to consider.

Do people have the choice of where they receive care regardless of the cost?

The federal government waiver procedure means that the overall cost of in-home care cannot exceed the overall cost of institutional care. We have never interpreted that to mean that on a person-to-person basis the cost of an individual plan cannot exceed some chosen budget figure. But we would look carefully at any individual plan that exceeds average institutional care.

What criteria are used to determine whether a person can stay in their home?

Basically the criteria are "can a person have their needs met there?"

If staffing needs require two or three staff at 2 a.m. to help with toileting, it may be time to look at a different model. The criteria are an individual plan that addresses needs, assesses risk and can be done reasonably. Where we cross the line is something that can only be determined on a person-to-person basis but our intent is to keep people at home.

Who makes the decision?

The majority of the decisions for senior and disability services is made by the person, their family, case manager and/or regional crisis staff and a provider.

If somebody is in comprehensive, 24-hour services, and wants a change in their situation, the rules allow their service dollars to be portable. That process can be used when there is real unhappiness.

Unfortunately, if you are in a



Mary Lee Fay, administrator of the state Office of Home and Community Supports

support services model, crisis is the only bridge to comprehensive services. It should not be that way, but right now it is.

Are there different standards for young adults with disabilities and seniors?

No. The same eligibility standards apply. The same nursing home waiver standards apply. Basically that means 300% of SSI plus criteria for need determined by levels of activities of daily living. There are 17 levels with 17 representing the least amount of assistance, such as shopping. We are now only able to make a person eligible at level 11. That is because of budget issues. By tightening eligibility to level 11, about 5,000 people have lost services since last February. [Editor's note:

The budget recently passed by the Legislature restore funding for levels 12 and 13.]

The needs of seniors and young people with disabilities are similar. The majority of seniors are served in their homes.

Currently we have a demonstration project in three counties called "Independent Choices." People are allowed to cash out their Medicaid and take the money and do what they want. It allows a method for choice that is not restricted by Medicaid rules that do things like prohibit paying a spouse to provide care. These are called "Cash and Counsel" programs. You get counseling and the cash.

Groups want different things. I don't think we want a program that says services are or are not available based on age. There is no need for separate eligibility criteria as long as there is choice built in.

Has the budget crisis changed the ability or method the state uses to seek and consider advocate and provider input in the decision making process?

No. In developmental disabilities and other services, I don't think any major policy decision has been made without advocate input. In fact, all of the changes I can think of—institution closure, medically fragile, etc.—have not only been the result of input but are actually an outcome of consumer direction. The budget crisis serves to drive us back to the table of listening to consumers and providers. It does not drive us away from it.

Ask OAC: New Staley Agreement

Q Why was the original Staley Agreement changed?

A Because of the state's fiscal crisis. While thousands of poor and disabled Oregonians were being terminated from medical, financial and support services, and while school years were being shortened across the state, some sacrifices were inevitable. When the original agreement was made, no one expected this crisis and the level

of human suffering that it has caused. In this climate, a guarantee of continued, if slower, expansion of services over a longer period of time seems proper.

Q How was Staley changed?

A Brokerage services and comprehensive services will be phased in over a longer period of time than was originally agreed.

Brokerages are to serve 1000 new people each biennium until all eligible individuals are receiving service. This is to be completed before June 30, 2009.

Non-crisis comprehensive services are to be similarly phased in so that 300 individuals receive these services by June 30, 2009.

The new agreement will remain in effect until June 30, 2011. This means that the state has agreed to provide the brokerage and comprehensive services

for four years longer than the original agreement.

Q When does the new agreement take effect?

A The state has already started to implement the new agreement because the legislature has provided adequate funding to do so. The agreement will not be formally completed until it is signed by all parties and approved by the federal court.

STALEY, Continued from Page 1

DD wait list when he was 18," Karen Staley says. "We knew there would be a wait. When the lawsuit was filed in February of 2001, he was still on the same list."

"In June of 2000 I was diagnosed with breast cancer," Karen offers. "Although my treatment was a success, it reminded me of my own mortality. I wanted to be around to help plan and carry out Jim's transition to his own home. I didn't want him to move in a crisis situation."

Jim had lived his whole life in his family home. He wasn't too keen on the idea of leaving. "We asked Jim, 'where do you want to live' and found out that he wanted to live right where he was, with us," Karen recalls with obvious concern. "We realized that he had no idea what an apartment was. He just could not imagine living anywhere but where he had always lived."

At about this time Karen's mother moved into an apartment for seniors and Jim began visits to his grandmother. "That is how he learned about apartments. When we asked him again he told us he wanted to live in his own apartment, with no roommates. He wanted to live alone," says Karen.

Once the lawsuit was filed and settlement talk began, the first step for the family was selecting a provider agency. "We chose Community Visions because I had a history of working with Executive Director Joe Wycowski," says Karen. "But more important, I knew

that the agency understood the importance of planning around the wishes and needs of one individual at a time."

Once a provider was chosen the family went to work planning Jim's transition. The technique of making a plan was important to them. "I wanted a plan that focused on what skills staff would need in order to work with Jim. One of the skills is patience because of his communication issues," Karen says emphati-



"I make my own choices. This is my home."

cally. Jim uses sign language. "We needed staff that could sign," Karen adds.

The same month that the lawsuit was filed, Jim hired Joy Baker of Community Visions to work with him. "We began by getting acquainted and then we went apartment hunting," says Baker. "This is the one Jim wanted." Once the apartment was chosen they began to do some serious work on transition.

It was nearly fifteen months from the beginning of the transition process until Jim moved into his own place on May 1, 2002. Looking back with great pride, Karen Staley says, "Once he moved he really moved. The first time he

came back to our house for an overnight visit was Thanksgiving. He knew right away that the apartment was his home and he wanted to be there."

Today Jim lives with staff he hired and who know their job is to work for him. His new roommate is Kim Hainley. She began her work in August. She worked six years for Loaves and Fishes, met Jim through his volunteer work, and made the change when it was offered. "I knew right away that

At the time the lawsuit was filed he was out of work.

"We go on job searches," states Joy Baker. "Jim can do almost anything. But the employment situation is hard. Lots of people are looking for work."

In the meantime Jim volunteers three days a week at Loaves and Fishes. "He handles the coolers for packaging meals. He counts the items for each delivery and stocks them. He operates independently, trains others and never makes a mistake," boasts Baker.

When asked what he likes best about his life, Jim's only hesitation is in deciding what to say first. Choice made, he says "Karaoke!" According to Karen, Jim sings Karaoke twice a week at a neighborhood bar. "He loves performing 'Knocking On Heaven's Door' and especially 'Your Mama Don't Dance and Your Daddy Don't Rock and Roll.'"

Jim's other enthusiasm is cooking. He shops with Joy Baker for groceries, picks what he wants and does most of his own cooking. His favorite home cooked dinner? "Baked chicken with rice." And breakfast? "I make great omelet's."

Jim's mom knows what she likes best about her son's life. "It's the little things. Like having his voice on the telephone answering machine. 'This is Jim Staley's house.'"

Adjusting himself in his easy chair, Jim echoes his mother's thoughts. "I make my own choices," he says. "This is my home."



Photo courtesy of Robbie Alvord

Emory Blackwell of Eugene

*Summer
fun at the
Oregon
Country
Fair*

STALEY, Continued from Page 1

and Persons with Disabilities. "The thing about human services is that they are born from values. Values such as least restrictive environment, options, choice, enhancing dignity, least cost that can meet an individual need, are values contained in our enabling statute. Values direct the work we do," she says.

For administrators, implementation of value-based programs has not been easy. "The last two years has very much been defending programs and not making progress," says Cathy Cooper, Deputy Assistant Director at Seniors and People with Disabilities. "But we have acquired optimism that the programs were not pulled apart altogether. We still have the foundation to move forward."

People with disabilities know what values mean

While administrators such as Cooper feel a sense of relief that programs have escaped elimination, consumers of services know how greatly their lives can be impacted by seemingly minor policy and budget decisions. Mike Volpe of Corvallis is a consumer advocate, member of the Oregon Home Care Commission and wheelchair user. He knows from personal experience how decisions can impact individuals.

"I once lived in a nursing home," he says. "For me, allowing people with severe disabilities to live in a place of their choice is a core value." But what Volpe calls "quality of life" cannot be achieved simply by honoring a person's choice of where to live. It also requires a support system to keep it safe and make it work.

"When you receive in-home support, as I do, you are responsible for the care you receive. But lots of us have no idea how to supervise and train staff. That may not sound like much to a person making budget decisions but it sure caused me to flounder. I have advocated for care receiver education for a long time. What I would like to see, but it's not going to happen anytime soon, is that each person receiving care in their own home would get training on how to do it. There was no training available to me."

While services are supposed to be based on individual needs, within the parameters of program budgets, some

consumers have felt that their individual programs were dictated not by their need but by budget decisions alone.

Mar Goodman of Cave Junction is the mother of a young adult son who receives services from the Intensive In-Home Supports Program. According to Goodman, the intent of that program is to support families that care for members with extraordinary needs. While emphasizing how grateful she is to the program, she also has felt that the values supposedly underlying its funding have not always been honored. Her son's fund-



Photo courtesy of Janice Richards

Janice Richards, Executive Director of Oregon Parent Training and Information Center.

ing was cut by 40%. "The higher ups decided, without a very careful review, that my son's budget was higher than it should be. That decision certainly increased the burden on me," she says.

Educational placements at risk

While adults worry that their services are being determined not by their needs, but by budgets, families and administrators in special education programs have clashed over the appropriateness of educational placements. Many families have questioned whether their child's placement is really designed to meet the child's educational needs or the administrative and financial requirements of the school district.

"Placement decisions in many cases raise the question, 'are we putting our kids on the altar of money?'" says Janice Richards, Executive Director of the Oregon Parent Training and Information Center. "Many IEP meetings held in Oregon are now so formatted. The team simply plugs in a name, eligibility, and the child is offered goals A through D. You get to pick a predetermined goal. We are

losing the individual because of money."

Richards also worries that the resources spent on special education are being viewed by educators as taking money that could better be used to meet school assessments required by the new federal No Child Left Behind law. "I was recently told by a superintendent that 'we' (the district) would have made the grade if it weren't for 'those' kids in special education. That worries me."

Chris Shank, staff attorney at the Oregon Advocacy Center, also sees placement decisions being determined by budgets. "Kids in Oregon may be more included but it is with fewer supports. No behavior plans for instance, just a placement. Schools are trimming at the corners without being super-verbal about it."

For children to receive the value-based educational services the law says they are entitled to, a well-informed and verbal parent is usually the only guarantee. An intake specialist at the Oregon Advocacy Center says, "parents are more reluctant to push these issues. People are intimidated by budget talk. A big problem is the constant recycling of new parents who don't know what to ask for."

"I am not willing to compromise my child's education," says Richards. "I know my rights and I know how to negotiate. That only comes from lots and lots of training and lots of knowledge. Until every parent or guardian has that knowledge, schools will make decisions based on money. Parents must learn to stand up and say 'this is not acceptable'."

Susana Ramirèz is the Special Education Advocate at the Oregon Advocacy Center. "Budget cuts are affecting our kids," she says. "These are federally mandated programs that are not supposed to be touched but they are being touched. Even when attorneys are present, money is brought up as a barrier." She agrees with Janice Richards that parent advocacy is the key. "We don't have enough legal training for parents on their rights. Without more trained parents, the federal mandates will just fade away."

Special education administrators are not unaware of the danger of money-guided placement. "Values are at the heart of where this conversa-

tion needs to go," says Maxine Kilcrease, former Director of Special Education for Portland Public Schools. "For me the question is, 'are our decisions authentically aligned with our core values?'"

"In the real world, the issue is, how do we stretch the money? Are our programs consistent with values, or are they something we created for adult convenience?" Kilcrease asks.

What are core values?

Of course, not everyone agrees on what core values are. "I think we are close to reaching consensus on values," says Laurie Powers. "Does self-determination mean individual budgets? Person centered planning? Microboards? What it is really about is control over your life. Money is just a part of that. It is not the defining ingredient."

But according to Tamie Hopp, Executive Director of the Voice of the Retarded, a national advocacy organization located in Rolling Meadows, Illinois, "self-determination is a trend, the latest in a long line of trends in mental retardation. It is painted with a very large brush."

"The deinstitutionalization movement eliminated choice," says Hopp. "To suggest that my child can live in a home with a white picket fence and untrained workers is silly. 98% of people are better off served in the community. But if choice is a value, then it must mean choice. Money keeps my child out of an institution and that is where my child needs to be."

Political process requires compromise

"Institution closures nationally are not being driven by values," says Bill Coffelt of Folsom, California and parent co-chair of the National Coalition on Self-Determination. "Closures are about cost saving. In California, and I suspect Oregon, advocacy has moved away from perfecting and developing self-directed community supports in favor of just protecting what we already have. Someone, some group, has to stand aside from the political process and keep the values alive."

Even advocates can feel pressured to compromise values, according to Coffelt. "Paid lobbyists tell us we must

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IDEA at risk

The Individuals with Disabilities Education Act (IDEA) is the major federal law governing special education.

Both the House and the Senate have passed IDEA reauthorization bills that would limit the procedural rights of children and families. Additional changes may be offered by legislators during the next step in the process (known as a Conference Committee). Set out below are some of the proposed changes that many families and advocates find particularly troubling.

Discipline changes

- ▶ Allows school personnel to remove a child from his or her placement for violation of any school rule without an assessment of whether the behavior is related to the child's disability. No hearing is required prior to removal. "Stay put" provisions are eliminated.
- ▶ Removes the requirements for a functional behavioral assessment, a behavior intervention plan and review of the appropriateness of the current IEP (individualized education program) and placement.
- ▶ States that when a child is removed, he or she is to be placed in a setting that en-

ables the child to progress toward meeting his or her IEP goals. No longer requires that the child receive the services and modifications described in the child's IEP.

- ▶ Allows states to pass laws or administrative rules that permit a child to be kept in an alternate setting indefinitely.

Due Process changes

- ▶ Encourages "early dispute resolution and voluntary binding arbitration" of disputes.
- ▶ Requires parents to meet with school districts before they can receive a due process hearing. Delays receipt of a hearing for 15 additional days.
- ▶ Notice to parents of procedural rights is no longer required upon each notification of an IEP meeting, re-evaluation of a child, or registration of a complaint.
- ▶ The notice of procedural rights no longer requires a "full explanation" but only a "description" of those rights.
- ▶ Hearing officer may not rule on school district's procedural violations.
- ▶ The right to appeal a due process hearing decision to the

State educational agency is eliminated.

- ▶ Creates a one year (House) or two year (Senate) statute of limitations. If a parent does not ask for a hearing about an issue within this time period, the issue may no longer be raised.
- ▶ Prohibits parents from raising an issue in a due process hearing that was not set out in their notice of request for a hearing.

Other changes

- ▶ Allows IDEA funds to be used for services and aids that also benefit non-disabled children.
- ▶ Short-term objectives in an IEP are to be replaced with quarterly progress reports resulting in no agreed-upon benchmarks for progress.
- ▶ Changes requirement that tests and other evaluation materials be provided in the child's naive language or other mode of communication. Now requires assessments and other evaluation measures to be provided "to the extent practicable in the language or form most likely to yield accurate academic and developmental data."
- ▶ Parents may be offered the "option" of a multi-year IEP up to three years in duration with "streamlined annual review." In the Senate bill this is limited to students 18 or

older.

- ▶ House Bill allows states to claim that they are immune from suit for violating the IDEA.
- ▶ House Bill allows ten states to be granted waivers from paperwork requirements in IDEA. This could include IEPs, parent notices and other important rights.
- ▶ There will be an effort to give Governors the unlimited authority to set the rates for attorneys representing parents. The rates for school district attorneys would have no similar limitation.

Due process hearings allow parents to have a skilled and objective third party evaluate whether a school district is obeying the IDEA. Parents will not have this protection if they don't know about due process because they are not notified; if they are delayed or steered away from using it; or if they are deterred because the process is made overly technical and assistance with the technicalities (getting a lawyer) is restricted. Due process procedures are especially important for children who are at risk of being removed from school because of behaviors associated with their disability.

Information for this article was provided by the Oregon Advocacy Center.

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compromise our basic values in order to have a place in the political process. If you are not able to compromise and support cuts you are marginalized as an advocate. You are not part of their conversation."

Education of consumers is the key

"There is an old Chinese proverb that says, 'where there is crisis, there is opportunity'," says Powers. "If one is to use crisis as opportunity then there has to be some foundation to ground your actions, and that foundation is values."

Bob Gettings agrees. "A decade of good budget times meant that most states could put off making tough decisions," he says. "The kind of environment we have now forces people to take risks and ask some very value-laden questions. As a community we need to focus on what those critical values are."

"Putting in place what it takes for a person to meet their life goals and dreams is what this is about," Powers adds. "You put a plan in place, but eventually you have to ask the person, 'did it happen?'"

"The two functions in this discussion that get the least attention are customer education and community building. Of course, person-centered plans and individual budgets matter and now a lot of people are talking about various quality assurance ideas. But none of that matters unless customers are informed decision makers and communities are welcoming," says Powers.

In the short term, values and budgets seem destined to clash. But, according to Powers, "In the end it comes down to people deciding how to best preserve the values that matter to them. How to live with freedom. Informed decision making is not just making choice but also understanding your responsibility."



Photo courtesy of Tim Wheat

Disability activists marched from Philadelphia to Washington, DC to support passage of legislation that would make the "money follow the individual." The march, sponsored by ADAPT, urged passage of MiCASSA, the proposed home-based Medicaid program which will make it easier for people to receive supports in their own homes and communities. The marchers left Philadelphia on September 4 and arrived in Washington, DC, 140 miles away, on September 17.

Fairview sale final

“Fairview Training Center property no longer belongs to the State of Oregon,” says Gerry Stolp, Manager of the Community Housing Section of Seniors and People with Disabilities (SPD). “The grounds of the old institution are the most attractive undeveloped urban real estate in Oregon and they are now sold.”

Sustainable Fairview Association, Ltd., of Salem, purchased the land. They plan to build residential neighborhoods with a mix of light commercial use and other community facilities. “Existing facilities will be partly destroyed and replaced and others will be renovated,” says Stolp. “The purchasers are a group of people interested in a sustainable environment. There will be cluster housing where you park your car and walk home, recycling of community water, etc.,” he said.

The purchase price for the sale is \$15,120,000 paid over five years. “The buyers put up \$950,000 in earnest money a year ago,” reports Stolp. “The first payment after that was made by the July 30 due date.”

Proceeds from the sale of the property will go into a Housing Trust Fund. According to Stolp, “The interest on the money can be used for housing adaptations for people with developmental disabilities that do not live in licensed facilities. Kids and adults, and people getting family support and services under the Staley agreement, will all be eligible.”

The State Department of Administrative Services will be reimbursed for the cost of upkeep on the campus since its closure, with the remainder going to the trust fund. “We will have \$2.3 million within a few weeks,” says Stolp.

“This is an exciting new resource for families and persons with disabilities to enhance their capacity to live in their homes and communities,” says Bill Lynch, director of the Oregon Council on Developmental Disabilities. “Families, advocates and self-advocates were involved in making sure this resource remained in the DD budget and they will continue to be involved in determining how the money is used.”

Administrative rules will guide use of the money

According to state administrative rules, money from the Housing Trust Fund may be used for adaptations in a primary residence when the project is necessary to enable an individual to function with greater independence in their home, is identified as a need in a support plan and is cost effective as determined by the Community Housing Section.

An eight-person Housing Advisory Committee will recommend an annual formula for distribution of funds, minimum and maximum amounts for grants, make policy recommendations and hear informal grievances upon request. Members of the



Photo courtesy of State of Oregon

Fairview Training Center

Advisory Committee are appointed by SPD and will include self-advocates and family members.

“One of the Housing Advisory Committee’s first tasks will be to approve rules for accessing the funds,” says Stolp. “I anticipate that applications will be available from case managers, through organizations such as Self Advo-

cates As Leaders and on our web site. The web site is not developed yet but will be operational soon. Additionally, we will provide technical assistance to applicants. Not only in filing the application but it developing their plan for the money’s use. We do not want this money to simply go to people who are good at filling out forms.”

Brokerages again open for business

With the adoption of the State budget for fiscal years 2003 – 2005, the freeze on brokerage enrollments was lifted. This was very good news for developmental disability advocates, who were worried about the future of Self-Directed Supports for Adults, which the brokerages administer. Services had been frozen since February 1 because of uncertainty about the budget.

As of September 1, brokerages again began enrolling new people into their services.

The order of enrollment for brokerage services is based on a

schedule established by the Department of Human Services’ Seniors and People with Disabilities in consultation with the Staley Implementation Group. The nine remaining brokerages were at various places in that order of enrollment when the freeze took effect.

Brokerages help individuals with developmental disabilities plan for and obtain Self-Directed Supports for Adults. Those services may be accessed by contacting your County Developmental Disabilities Program Office.

Look who’s reading the Clarion!

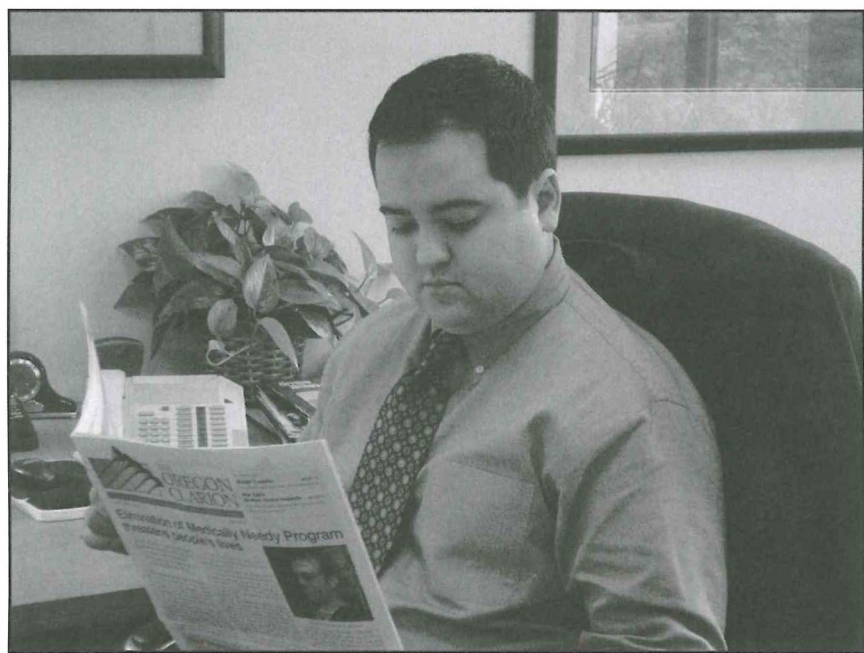


Photo courtesy of Rep. Dalto

State Representative Billy Dalto takes time out to read *The Oregon Clarion*. Rep. Dalto volunteered time during the legislative session to support Parents In Action, a Salem family advocacy group.

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