

THE ADVOCATE

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GOVERNOR SIGNS WAITING LIST BILL

The Waiting List Bill, passed at last by the Illinois House AND Senate, was signed into law on August 11, 2003, capping the final chapter of a 10-year campaign by Advocates United members and other advocates. Early this year, Advocates United asked State Representative Renee' Kosel (R-81) and State Senator Debbie Halvorson (D-40) to again sponsor the bill as they promised they would at the September, 2002 Legislative Forum sponsored by Advocates United and co-sponsored by 75 other organizations serving and/or advocating for persons with disabilities. Representative Kosel and Senator Halvorson came through as promised and have earned the gratitude of thousands of Illinois citizens with disabilities and their families. Will Illinois finally pull its head out of the sand and stop ignoring people with disabilities? It's now up to Governor Blagojevich and his Department of Human Services to implement the new statute. It always was ultimately in the Governor's Office in previous administrations where the public policy of neglect was sanctioned. It will be in the Governor's Office where that policy can be changed. Hopefully, the signing of this bill signals a new direction, which could finally bring about full citizenship for Illinois residents with disabilities. Illinois can at last pass the test posed by Hubert Humphrey to judge the moral character of a society based on how it treats its most vulnerable citizens; children, the elderly and persons with disabilities.

PERSISTANCE FINALLY PAYS OFF

Early in 1994, Advocates United members voted to make the waiting list our number one priority. In position papers, letters to public officials and in this newsletter, the "waiting list crisis" was featured. In the October 1994 Legislative Forum held at the Joliet Public Library, it was THE principal topic of discussion. Early on, the effort was made to get the State bureaucracy to voluntarily set up an official, State sanctioned waiting list as nearly all other States had already done to serve as a basis for planning and to give hope and a sense of security to parents and family members who care for the vast majority of persons with disabilities. They could be reassured that when the time came, they were on the State's radar and could count on needed assistance. Many legislators helped in this effort by holding public hearings and urging the administration to establish a waiting list so they would know what the need was and could plan and budget accordingly. The former Secretaries of the Department of Human Services and their Deputy Director for Developmental Disabilities unambiguously affirmed that they had no waiting list and had no intention of establishing one. They even blamed the Legislature saying they didn't trust legislators to care about people with disabilities enough to budget additional resources. They advised legislators that the lack of a waiting list would prevent a lawsuit. About this, they were dead wrong. But nevertheless, this attitude persisted, head in the sand and both feet planted firmly in midair, up until last summer when in testimony under

oath in Federal District Court in Chicago, State officials scorned community provider waiting lists and claimed they knew of no person with a developmental disability who was waiting for services in Illinois. It would be unfair though to say that State officials did nothing. Impelled by questions by members of the Senate Human Services Committee about the lack of any plan, the Department of Human Services set about to devise one. Unfortunately, information about the needs of actual people waiting for services in the community was inadmissible. Later with the Olmstead decision of the U.S. Supreme Court calling for “a comprehensive and effective plan and a waiting list that moves at a reasonable pace,” DHS set about to do an elaborate “needs assessment.” Thousands of surveys were sent out mostly to people who were already receiving services. They, of course, mostly said everything was fine. Several organizations including Advocates United sent out the surveys at our own expense to our members, many of who weren’t receiving anything. The State’s instructions to those responding were that they should not identify themselves except for the last four letters of their social security numbers. That way, reasoned the State’s lawyers, State officials could “truthfully” testify in court that they didn’t personally know anyone in need of services. How could they? The attestations of State officials in charge of services for people with disabilities that no one was in need, gave cover to the Governor’s Office and his Bureau of the Budget to virtually shut down for the past 10 years any new expansion of services, or even as in the case with services for people with mental illness, cut back on what pitifully few services were there in the first place.

ADVOCATES TAKE THE LEGISLATIVE ROUTE

What State officials wouldn’t do voluntarily could be accomplished through legislation. When requests to Governors Edgar and Ryan to order their staff to put a waiting list in place went unanswered, it was decided that we would approach legislators to sponsor a bill to compel the bureaucracy to establish a waiting list. Several times, Rep. Renee’ Kosel was principal sponsor of the bill in the House with numerous co-sponsors of both parties. It passed unanimously each time. Sponsored in the Senate by former Senator Bill Mahar (R-) and again co-sponsored by many from both parties, former Senate President James “Pate” Phillip (R-) would repeatedly effectively kill the bill by sending it to the Senate Rules Committee, the graveyard for bills Phillip didn’t want to pass. At the September, 2000 AU Legislative Forum, Senate Minority Leader Emil Jones, Jr. (D-) stood up and promised that if he ever became President of the Senate, he would see to it that the bill went through. That didn’t happen that year and once again Phillip killed the bill in the Senate. Expecting the same in 2001, AU decided to confront Senator Phillip to find out why he kept killing the waiting list bill. After numerous attempts, AU President Dan Hecht finally succeeded in speaking on two occasions with Senator Phillip. He admitted he was acting on information from the Governor’s Office opposing the bill, claiming it would spark lawsuits and cause the State to have to spend some money on people with disabilities who were eligible and in need. He said the Governor’s people told him it would cost \$100 million. There was no money available. Meanwhile, the deal was going down for \$400 million of the taxpayers’ money to build a stadium for the Chicago Bears, a private business. The bill was again buried in the Rules Committee of the Senate.

At the 2002 AU Legislative Forum, Senator Halvorson again promised to sponsor the bill in the Senate and its eventual passage if Senator Jones was Senate President. That's what happened and now Governor Blagojevich has finally signed the bill into law.

IN UNITY THERE IS STRENGTH

Through the years of struggle since 1994, Advocates United has been joined by a number of other organizations advocating for the waiting list bill. Without this united effort, the progress made probably wouldn't have happened. Special mention should be made of the ARC of Illinois whose lobbyist met with the State to negotiate more "acceptable" language for the bill that would mollify the States' lawyers and bureaucrats. People say that Department of Human Services Secretary Adams favored the bill and, of course, this helped tremendously. By the way, we don't call it the Waiting List Bill anymore but the DHS-Cross Disability Database Bill. Whatever it is called, don't forget to send a thank you note to the Governor, to Senator Halvorson and to Representative Kosel. Their addresses are on Page 2.

APPEAL COURT REVIVES BOUDREAU V RYAN

OUT OF COURT SETTLEMENT EXPLORED

First, the bad news. In an April 7th, 2003 opinion, a three-judge panel of the Seventh Circuit, U.S. Court of Appeals affirmed in part Federal Judge John F. Grady's dismissal of the Boudreau v. Ryan lawsuit now known as the Bruggeman V. Blagojevich. The plaintiffs, the parents of adult children with developmental disabilities, had sought services in community based group homes or CILAs. Even though eligible for regular Medicaid funded developmental disabilities services, the plaintiffs were denied access to these **Medicaid Waiver** services since the State claimed they did not meet the State's emergency criteria for admission. Instead, the State told them they could go to community ICFsDD (but not CILAs) even though virtually the only appropriate, available vacancies were two hundred or more miles away making continuing family contact virtually impossible. Now, the good news. While the Court of Appeals did not find in the plaintiffs' favor under the Medicaid statute, they did vacate and set aside Judge Grady's dismissal of the case under the Americans With Disabilities Act and Section 504 of the Vocational Rehabilitation Act. "The Advocate" has learned that Hinshaw & Culbertson, the law firm hired to represent the State, was recommending an appeal to the full Court of Appeals, 2/3rds of whom would have to approve hearing such an appeal. Even though this appears unlikely, it does further delay possible relief for the plaintiffs and, of course, keeps the taxpayer funded meter running for Hinshaw & Culbertson. If the appeal is not filed or if it fails, the case will be sent back to Judge Grady in Federal District Court to be heard probably in the fall.

APPEALS COURT AFFIRMS PLAINTIFFS STANDING

The Court of Appeals for the 7th Circuit, in a 13 page decision written by Federal Appeals Court Judge Richard Posner, rejected Federal District Court Judge John Grady's finding on which he had dismissed the entire case ruling that the plaintiffs "... lacked standing to press their claim to medical assistance (developmental disabilities services)...furnished with reasonable promptness to all eligible individuals, available in all areas of the State not less in amount, duration or scope than medical assistance made

available to other such individuals, and the right to choose providers from among those qualified and in a manner consistent with the best interests of the client.” (Judge Grady)

Judge Posner, after finding that the plaintiffs had standing to bring suit, then proceeded to examine whether the plaintiffs’ rights under the Medicaid Act had been violated. While the State acknowledged that the plaintiffs had a right to mandated Intermediate Care Facilities for the Developmentally Disabled (ICFsDD) services (in large community based ICFsDD or in ICFsDD 16 or Fewer), the vast majority of vacancies in such facilities were in southern Illinois. Meanwhile, the State maintained that the plaintiffs had no right to Medicaid waiver vacancies in Community Integrated Living Arrangements (CILA) which were right in their backyard. State officials testified they were reserving these only for emergencies, State operated facilities’ discharges and conversions of ICFsDD that the State was encouraging. Several qualified ICFDD providers from the Chicago Metro Area testified that they would be willing and able to develop new ICFsDD in small, 4 and 6 bed group homes in the Metro area for the plaintiffs. State officials testified that they would not allow this claiming that they considered any ICFDD licensed facility, no matter how small, to be more “institutional” than any CILA or living at home indefinitely with family caregivers. The State officials even revealed in court that they were actively working to reduce the number of ICFDD “beds” (mandated) by conversion to CILA “beds.” (not mandated) In fact, State officials’ testified that there had been discussion with the State’s largest provider of ICFsDD to convert 1000 of them to CILA licensure. The provider in question, midway through the trial, suddenly withdrew its offer.

Arguing from the Medicaid statute’s requirement that services should be provided “in a manner consistent with the best interests of the client,” the plaintiffs’ attorneys introduced testimony from a well know and respected psychologist in the developmental disabilities field that summarized research as to the benefits to most people with developmental disabilities of maintaining contact with their families. With most mandated vacancies in southern Illinois, this would not be possible. The State dismissed this testimony as immaterial since, in their view, people with developmental disabilities didn’t need to be placed near their involved families.

COURT REJECTS PLAINTIFFS MEDICAID LAW RIGHTS CLAIMS

So while the Appeals Court affirmed the plaintiffs standing, it nevertheless rejected on the merits their claim and entitlement to reasonable promptness and identical services Statewide tailored to each ones’ unique needs. The judges considered these unattainable goals not envisioned in the statute. As to the right to obtain needed medical services from a qualified provider who undertakes to provide such services, the judges interpreted the law to mean a choice among available services not requiring the State to create or authorize new services. Finally, the right to services in the best interests of the client, in this case close to the family, is insufficiently defined to be justice able and. ...cannot be interpreted to create a private right to action.”

Thus all claims based on the Medicaid Act fail. This could be appealed to the Supreme Court if the justices there would accept it.

COURT OF APPEALS REMANDS CASE TO GRADY

The Court of Appeals went on to strike down Federal District Court Judge John F. Grady's dismissal of the suit for lack of standing under Section 504 of the Vocational Rehabilitation Act and the Americans With Disabilities Act. Both of these statutes require that "recipients (of federal funds) shall administer programs and activities in the most integrated setting appropriate to the needs of qualified handicapped persons." The Appeals Court remanded this part of the suit back to Judge Grady recommending consideration of the parties and the federal district court judge of the words of the Olmstead Supreme Court decision..."if the state were to demonstrate that it had a comprehensive, effectively working plan for placing qualified persons with mental retardation in less restrictive settings and a waiting list that moves at a reasonable pace..." Illinois has neither. "The issue on remand", write the Appeals Court justices, "will be whether Illinois had a plan orientated to that end for developmentally disabled adults."

The State may have painted itself into a corner in its defense by its insistence that all ICFsDD are more institutional than all Medicaid Waiver CILAs. Later they modified this argument to say that staying at home with aging caregivers with no services was the least restrictive setting. Nevertheless, Home Based Support Services are also rationed "for emergencies only."

OUT OF COURT SETTLEMENT EXPLORED

It appears that the new Attorney General Lisa Madigan is taking a second look at this case. She has apparently decided not to appeal the U.S. Court of Appeals decision as recommended by Hinshaw & Culbertson. An offer to settle out of court from the plaintiffs is on the table under which the State would agree to provide services to the named plaintiffs and to develop an effective plan to serve qualified people waiting for services and a waiting list that moves at reasonable pace. In return, the plaintiffs would drop the suit and desist from filing further suits unless the State reneged on its promise. As we go to press, Attorney General Madigan has reached no decision. If she turns it down or fails to respond in reasonable time frame, it will be back to Federal District Court in the fall.

THE PRESIDENT'S POTPOURRI

Dan Hecht

We are all thrilled with the passage of the Waiting List Bill and the Governor signing it into law. Congratulations to all of our members who worked so hard through the past ten years to help make this happen. This has been one of our primary objectives since 1994 topping our agenda at five legislative forums and numerous monthly meetings. Over the years, our members have testified at legislative hearings, written letters to the Governor and every member of the General Assembly, spoken out on countless occasions, met with all kinds of State officials. But now that we have reached this goal, it is not yet time to rest. We must advocate that the statute be implemented "to assure quality life choices for all people with disabilities." That's our mission.

Congratulations to Representative Renee Kosel who has kept faith and continued to sponsor the bill despite seemingly overwhelming obstacles. In the 2002 legislative session when representatives were limited to only 5 bills apiece, Representative Kosel made the Waiting List Bill one of hers. We owe her a lot. We also want to thank Senator

Debbie Halvorson who was chief sponsor of the bill in the Senate. She promised to do just that at the 2000 and again at the 2002 Legislative Forums and she kept her promise. Thousands of Illinois citizens with disabilities will benefit from this legislation. Illinois will at last have the information about the needs of its citizens with disabilities so we can have a “comprehensive and effective plan and a waiting list that moves at a reasonable pace.”

Advocates United members voted to honor Representative Kosel and Senator Halvorson with “Legislator Of The Year” awards. Maybe we should have a “Legislator Of The Decade” award for them. That’s how long it took. Thanks again.

At the wish of the membership, I have been urging Attorney General Madigan to settle the Boudreau V. Ryan (now called the Brueggeman v Blagojevich) lawsuit out of court. Otherwise this will drag on indefinitely and cost the taxpayers hundreds of thousands of dollars more. I attended many of the Federal District Court sessions last year as did our immediate past president Tom Ryan. We are convinced that people with disabilities are having their rights violated. Write Attorney General Madigan as I have already done in your name urging her to settle out of court and instead take the side of Illinois citizens with disabilities in enforcing their rights under the law.

While you have your pen and writing paper out, please send a thank you note to Governor Blagojevich for signing the Cross Disability Data Base Bill, aka the Waiting List Bill. We want him to know that we take it very seriously. While you are at it, send a thank you note to Representative Kosel and Senator Halvorson too. Here are the addresses:

The Honorable Rod Blagojevich
Office of the Governor
Thompson Building—16th Floor
100 W. Randolph Street
Chicago, Illinois 60601

The Honorable Renee Kosel
19201 S. LaGrange Road
Suite #204
Mokena, Illinois 60448

E-Mail: rkosel@aol.com
The Honorable Debbie Halvorson
241 W. Joe Orr Road
Chicago Heights, Illinois 60411
E-Mail: senator@debbiehalvorson.com

The membership voted to try to sponsor an area wide meeting with DHS Secretary Carol Adams and her leadership staff from Developmental Disabilities, Mental Health, Rehabilitation Services and the Inspector General. All 75 of our partner organizations from the Forum would be invited. I’m working hard on this but progress is slow.

**P.S. Our new address is 1740 W.
McDonough St., Joliet, IL 60436**

“THE ADVOCATE” is the publication of **ADVOCATES UNITED. Advocates United’s mission** is "WORKING TOGETHER TO ASSURE QUALITY LIFE CHOICES FOR ALL PEOPLE WITH DISABILITIES."

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Editorial Staff:

Dan Hecht, Editor. Staff: Richard Bell, Dieter Burr, Diane Gilbert, Mary Mayer, Tom Ryan, N.S. Worthy

Mail articles to: “THE ADVOCATE”

c/o Dan Hecht, Editor

Advocates United

1740 W. McDonough

Joliet, IL 60436 #815-741-0800

or e-mail letters or articles to Advocatesunited@aol.com

Letters to the Editor are Welcome

BELL'S BRIEFS

By: RICHARD W. BELL

A NEW BROOM SWEEPS CLEAN

There are a lot of “new brooms” in Illinois since the last election. we advocates are hoping they start sweeping soon. The public policies of the past administrations toward people with disabilities need priority attention in the cleanup. With the change in leadership in key positions, the Governor’s Office, Presidency of the Senate and the Attorney General, hope has resurfaced in the advocacy community that former policies of neglect, evidenced by lots of lip service but a dismal record of action, will be swept away.

Lest anyone doubt the reality of a pervasive policy of neglect, one only need consult the national comparative studies conducted over the past 20 years. The seventh wealthiest state in the union is mired near the bottom in nearly every measure and is still sinking compared to all of the other states. The downward pattern has persisted for the past 20 + years. If anyone has any lingering doubts, I recommend reading the 2000 plus pages of sworn testimony from the Boudreau v. Ryan lawsuit in federal district court in the Northern District of Illinois. There the real public policy of Illinois is revealed in stark relief. It had been reflected over the years obliquely in annual state budgets and the annual ritual skirmishes, not always successful, over no cost of living increases and minimal expansion of services of all kinds despite abundant evidence of a rapidly growing waiting list. Year after year, advocates for people with disabilities would come away from these exhausting efforts with little more than bones to fight over and too often not even that. But nakedly revealed in the pages of the transcripts is conscious and deliberate neglect characterized by ostrich management, “the State doesn’t know and doesn’t want to know about the needs of its citizens.” The only exception will be a

handful of “emergencies.” One gets the feeling that they were only included because of the potential for adverse media attention. The state claims Medicaid, ADA, Section 504 of the VR Act confer no rights on eligible people to choose services they need in the setting they feel best meets their needs. Remember, the State doesn’t officially know anyone in need of services. But more disturbingly revealed is that State neglect was not even benign. Witness the behavior of learned counsel for the state and the \$1.5 million paid for legal defense services, all spent on preventing people who were eligible for services from getting them. Where are the brooms? Bring in the Brooms.

So how are we doing so far? Not bad where the State Senate & House are concerned. The across the board cuts were restored and a 4% cost of survival increase passed. Even more significant in sweeping away the old policy of neglect was the passage of the “cross disability data base” bill. After repeated unanimous passage in the House over the years, this bill was repeatedly buried by then Senate President James “Pate” Phillip. Finally reached for an explanation by AU President Dan Hecht, Mr. Phillip told us he opposed anything that the Governor’s Bureau of the Budget told him “cost money.” At our last three legislative forums, Senator Emil Jones, Jr. promised he would see to it that the bill passed if he was elected Senate President. He was and he did. Yes, there is progress in the Legislature.

Our new Attorney General Lisa Madigan has some sweeping to do. Her predecessor, Jim Ryan, hired Hinshaw & Culbertson to fight the plaintiff parents in the Boudreau V. Ryan lawsuit rather than advocate that the State follow the ADA and Section 504 of the Vocational Rehabilitation Act for its most vulnerable citizens. Thus it appears that the taxpayers’ money was spent in furtherance of the State’s public policy of neglect. After the 7th Circuit remanded the case back to the U.S. District Court, learned counsel for the State wanted to appeal, keeping the meter running, of course. Indications are that the Attorney General Madigan rebuffed that recommendation. Meanwhile, attorneys for the plaintiffs offered to settle out of Court. The offer would involve provision of services for the plaintiffs within three to six months. The settlement would also include an agreement by the State to develop a comprehensive and effective plan along with a waiting list that moves at reasonable pace, in other words, the Olmstead decision. This is what the Court of Appeals recommend District Court Judge Grady focus on in taking up the case again. But if it comes to that, many more months will pass; more of the taxpayers’ dollars will be spent defending a bankrupt public policy. Attorney General Madigan has an opportunity to sweep away the old policy of neglect and do the right thing. She hasn’t responded yet. We all hope she will soon. So where are we with Governor Blagojevich? The extreme budget crisis tends to obscure things. His original budget contained no cost of living increase (nothing since July, 2000) and imposed a 1.25% cut across the board cut. Not a good start. But then he signs a budget bill that awards a 4% cost of living—many of us call it a cost of survival—increase. He signs another budget bill that restores the 1.25% cut but he then he vetoes a very modest expansion of needed services when thousands of people and families waiting. On top of that, he decrees that 2% of everything including community services be put into reserve. Now we are back to a 1.92% increase but that’s a lot better than the original 3.25% cut. Then just last week he signs the Waiting List Bill into law.

After 10 years of advocacy, it’s hard to believe it finally happened. Mixed signals! History has shown repeatedly that in those States with much better services for people

with disabilities, the one indispensable ingredient for change and improvement is a conscious and sustained interest and commitment of the governor. The other day, the Governor commenting on a demonstration for higher wages for personal assistants, was quoted as saying people with disabilities had done well in the budget process. Is he fully aware of the extent to which the public policy of neglect of previous administrations has ravaged the service system for people with disabilities? This is only the beginning. The Waiting List Bill will mean nothing unless it is taken seriously. Band-Aids won't serve for a patient who needs intensive care. That's where we advocates come in. We have an obligation both to people with disabilities and to our new Governor to make sure he knows how bad it is and how much Illinois citizens with disabilities and their families are suffering from the old neglect. Governor Blagojevich, pick up that new broom and stand beside Illinois most vulnerable citizens as they seek to change public policy and put Illinois back on the map.

GOVERNOR'S 2004 BUDGET FIXED

With the worst budget deficit in the history of Illinois looming, people with disabilities and those who serve them were still hoping for the best while waiting for Governor Blagojevich's budget to emerge. After all, people reasoned, since we didn't share the bounty in times of plenty, maybe we would be spared the pain in lean times. Maybe a new administration would reverse the past 20 years of indifference and neglect toward people with disabilities which has propelled Illinois now to a ranking of 47th in the nation in fiscal effort.

Well, people were partly right. When the Governor announced his budget on April 9th, we didn't see anything like the \$100 million + in cuts in Governor Ryan's last budget, 2/3rds of which was later restored by the Legislature. There was suffering as the Governor had promised everyone but the pain was limited to a 1.25% across the Board cut for all programs serving people including people with disabilities.

DISASTER THREATENS COMMUNITY

What budget planners may have thought a token cut for community providers looked to them like the straw to break the camel's back? Shortly after news of the cut, it was also revealed that an additional 2% of all community funding was to be put "in reserve" meaning it could be cut from their State funding allocation at any time during the fiscal year. What was a 1.25% cut suddenly becomes 3.25%. Add to that the lack of any cost of living increase for community workers who haven't had a raise to help feed their families since July 1, 2001. Worse yet, there was no cost of doing business increase again for the third year in a row. Since July, 2000, the Consumer Price Index had risen by 11% while State funding to cover the cost of doing business for community programs has risen 2.5%. The reality was far worse. Across the State, providers reported increases in expenses such as employee health care coverage, workers' compensation and liability insurance rates, utilities and transportation as high as 60 to 70% since the last cost of doing business increase in 2000. If you add the 3.25% cut and reserve to 8.5% unreimbursed inflation and it adds up to a 11.75% shortfall.

STATE PAYMENT DELAYS WORSENS SITUATION

Most community service providers have been forced to wait 3 and 4 months to be paid for services provided. Any operating reserves that could be used to bridge the gap between providing services and getting paid for them are long gone, depleted by annual

loses due to a lethal combination of one of the lowest reimbursement rates for services in the U.S. and years of no cost of living or cost of doing business increases to address inflation. Many, if not most, community service providers are up to their eyeballs in debt, borrowing from their local banks to finance the State's deficit at 5.25% - 5.5% interest, an expense the State refuses to recognize or reimburse.

Creditors are charging 1.5% interest a month on the balance of unpaid bills that can't be paid because of late payments by the State. By the way, interest expense is not reimbursed by the State. Some community providers are grabbing for a temporary fix called the "once in a lifetime hardship letter" to the Illinois Comptroller's Office begging that their payments be moved up in the long line of bills waiting to be paid. The Illinois service system for people with disabilities is already severely weakened by 20 years of indifference and neglect. People with disabilities, considering the national ranking of 47th in effort, haven't been on the back burner. They haven't even been on the stove.

ILLINOIS SERVICE SYSTEM FACES FURTHER DECLINE

Unless something was done to reverse the cuts, the 2% reserve, inflation ignored for the fourth year in a row, the cost of borrowing money to make payrolls and a 20 year long public policy of neglect and indifference, the Illinois service system for people with disabilities was headed for disaster. We are already seeing the signs.

- ◇ Programs closing or going out of business.
- ◇ No wage increases for employees now for the third year, further decreases and loss in employee benefits, increased turnover, increased vacancies that can't be filled, fewer trained and experienced staff, staff working longer hours or two jobs to survive, greater risk of abuse and neglect and psychological trauma from caregivers leaving.
- ◇ Maximizing program capacities, e.g. CILAs formerly serving 5 or 6 now seeking to increase to maximum capacity of 8. Increasing staff /client ratios leading to greatly reduced individualized programming. Reducing services to absolute minimums with more options being classified as service enrichments or add ons not covered by the State funding and requiring the individual or the family to contribute. Transportation is one such service that the State claims to pay for but doesn't.
- ◇ Continuing to ignore growing numbers of people in the community waiting for services. Illinois still has no State sanctioned waiting list. This may soon change since the Governor signed the WL bill.
- ◇ Further erosion of individual's rights such as being able to choose providers, types of services, roommates, etc.
- ◇ Deterioration of physical environments and equipment as providers lack funds for replacement.
- ◇ Increased time and energy diverted from providing programs to fund raising. Increased appeals to individuals and to families to commit to participate in fundraising in cash and/or in kind.

LEGISLATORS LISTEN TO PROVIDERS AND ADVOCATES

Advocates United members voted to support the DO THE RIGHT THING COALITION in their effort to advocate for relief from this intolerable situation. AU voted to send every member of the General Assembly a letter urging them to reverse the cuts and vote for a COLA. Included in our mailing were position papers from the Center For Tax and Budget Accountability suggesting alternatives to cutting services. A second paper

recommended changes in the antiquated and unfair Illinois tax system. Where do we stand at the moment?

1. The Governor signed the budget bill restoring the 1.25% across the board cut in funding.
2. On July 11th, a highly placed staffer in the Governor's Office assured community providers that the 2% reserve did not apply to them. Shortly thereafter, this was revoked.
3. On June 22, the Governor signed the budget bill that funded a 4% cost of living/cost of doing business increase for FY2004. With the 2% reserve deducted from all community program funding, the actual COLA will be 1.92%, the first such increase since July 2000.

Yet, despite the budget deficit, significant expansion of community programs could have occurred if Illinois would only seek Medicaid reimbursement for programs and services already being funded with State dollars eligible but not matched with federal dollars under the Medicaid Program. Experts who have studied the State's program, have put the potential increased Medicaid reimbursement at between \$145 to \$230 million. Ask your legislators to look into this. Illinois ranks near last among the States in accessing Medicaid dollars.

LINCOLN DC MAY RISE FROM THE ASHES

Nearly a year after the last residents were moved out and the 30 existing buildings abandoned and boarded up after 125 years in operation; there are again signs of life at the former Lincoln Developmental Center. Rumor has it that Department of Corrections guards briefly apprehended some people who were recently visiting the LDC cemetery. Part of Lincoln DC was closed several years ago was converted to a prison. More auspicious though was the visit of the Lincoln Advisory Task Force on the morning of August 5th preceding a daylong meeting to help decide a future for the shuttered facility. During the gubernatorial campaign last fall, both candidates vowed they would reopen Lincoln DC, closed down by former Governor George Ryan, if elected. Governor Blagojevich appears determined to make good on his promise. His budget earmarks \$7 million to remodel a portion of the vacant center and another \$5 million for staffing costs.

LINCOLN TASK FORCE CONVENED

Governor Blagojevich asked DHS Secretary Adams to convoke a Task Force to recommend what should be done. The Task Force held its first meeting on July 15th with the assignment from Secretary Adams to the various factions represented to work together to find agreement on a new vision for Lincoln that could be the model for other state facilities. One gubernatorial ground rule in any plan was that the present campus had to be used somehow. The Task Force, attendance by invitation only, brings together most of the previously warring parties who supported or opposed the closure in the first place. Representatives from AFSCME (the American Federation of State, County & Municipal Employees Union), the Lincoln Parents' Council, Senator Larry Bomke & Representative Rich Brauer who represent the Lincoln area, Mayor Beth Davis of Lincoln, several statewide advocacy organizations including the Illinois Association of

Rehabilitation Facilities, the Coalition of Citizens with Disabilities, the Illinois Council on Developmental Disabilities and UCP of Illinois. Several proposals surfaced in the meetings Secretary Adams refloating an idea originating with the Governor's Office of building four, 10 bed homes. An alternative idea proposed by veteran advocate Don Moss featured building of 10, four bed homes scattered about the campus, then selling off the remaining lots at reduced rates to community people to build single family residences between the CILAs (group homes) for a kind of "reverse integration". Whatever the final solution, the Task Force was faced with a much more mundane decision on August 5th. Should the Lincoln power plant be fired up again, a process which takes 60 days and which would cost \$1.3 million annually, to maintain the 30 existing but vacant buildings on the 10 acres campus through the winter. This has become an issue since, whatever the final reincarnation of Lincoln is to be, the target date for reopening has been pushed back by state officials from January 1, 2004 to next spring or summer. Lincoln Mayor Beth Davis says the reopening can't be too soon. The Lincoln closure reportedly put 200 of the town's residents out of work, 400 homes are up for sale and the county unemployment rate is at 6%. Stay tuned.

TRANSITION TALK

by **MARY MAYER**

At the April Advocates United meeting, guest speakers presented a panel discussion on Adult Vocational and Developmental Training Programs. Five community based service providers were represented. A lot of good information was presented which I am passing on to our readers.

SERTOMA CENTRE, 4100 W. 127th Street, Alsip, Il 60658 was represented by Paula Phillips, Associate Director. (708-371-9700)

The **SHELTERED EMPLOYMENT** Unit offers 13 different programs within two day program buildings currently serving 200 individuals. Day programs consist of subcontract work, social skills training and current events based on the client's level of functioning. Sertoma also offers a mental health program serving 50 individuals dealing with psycho-social problems. Counseling is a vital part of this program.

For high school students with special needs, Sertoma offers an ISBE approved school-to-work transition program where IEP goals are addressed along with vocational opportunities both in house and in the community. (Contact person is Avis Hughes.) Programming is also provided for senior citizens with disabilities.

SUPPORTED AND COMPETITIVE EMPLOYMENT (Insight Program) offers short term as well as long term supports ranging from 6 months to 5 years in real community jobs. Community based assessment sites/job tryouts are available. Sertoma has an 80%

placement rate. Contact person: Laura Gardner. Sertoma also provides programs in the areas of janitorial and security guard training.

CORNERSTONE, 800 Black Road, Joliet, Ill 60435 * 815-774-3257

Contact Person: Cindi Lapicki. Cornerstone serves Joliet to Kankakee Grundy and South Cook County. A variety of programs are offered including three day a week activity programs, a variety of daily classes, social skills instruction and a “drop in center” for part time workers.

The main focus is on community involvement featuring community based vocational assessments with over 200 employers. Both supported and competitive employment is available providing short to long term community supports.

SOUTHSTAR SERVICES, 1005 West End Avenue, Chicago Heights, Il 60411 * 708-755-8030. Contact Person: Sue Hendrickson. Currently serving over 250 individuals from Bloom, Bremer, Crete, Monee and Rich Townships. Developmental Training is offered including programs for persons with severe to profound mental impairments. Other programs available include Vocational Evaluation featuring community-based assessments, Supported Employment, a Supported Volunteer Program, a Senior Program for individuals with disabilities 55 and over. SouthStar also provides community living services currently operating 4 group homes.

Note: Cornerstone, Sertoma and Kankakee County Training Center also offer residential services.

KANKAKEE COUNTY TRAINING CENTER, 333 Schuyler Ave, Bradley, Il 42130. * 815-929-2485. KCTC serves residents of Kankakee County. KCTC operates Developmental Training Programs as well as large production workshops (integrated workforce) and prevocational skill programs. Also available are computer and functional courses and vocational training in housekeeping and food preparation. KCTC serves many residents of the Shapiro Developmental Center. Other programs offered include Supported Employment, “Camp Wellness”, a fitness and dietary program and a program for senior citizens with disabilities.

SOUTHWEST COMMUNITY SERVICES, 6775 Prosperi Drive, Tinley Park, Il 60477 * 708-429-1260. Contact Person: Lynn Zona at extension 1233. SCS serves individuals with qa primary diagnosis of developmental disability at this location. They also operate Community Enterprises/Employment Services at Palmer Blvd., Homewood, Il 60430. * 708-957-7060 This location serves people with a primary diagnosis of mental illness.

The Tinley Park location serves 200 individuals in a variety of programs including vocational rehabilitation within the training center. Also offered is Supported Employment, Independent Living Skill Training, “drop in” club with 1 or 2 community outings per month, a partnership with the South Suburban Special Recreation Association and a program for senior citizens with disabilities. The Homewood Facility provides Employment Skill Training, Psycho-Social Programs, Independent Living Skills Training, Vocational Rehabilitation Training, Vocational Evaluation, Supported Employment and Retail Training.

COMMON THEMES among all the presenters were:

1. Individuals must apply and be eligible for Public Aid (Medicaid) in order to secure possible funding for placement after high school.
2. Be sure to complete applications early, starting at age 14, in order to be put on the extensive waiting lists.

For further information regarding transition, contact Mary Mayer at 708-339-3435.

SOCIAL SECURITY AND YOU

**By Patrick Rogers, Field Representative
Social Security Administration**

I think there's a lot of confusion about the income you receive from various sources each month and your ability to get Supplementary Security Income (SSI) payments. Perhaps I can help clear it up.

First of all, you can have other income and still qualify for SSI. And if you currently receive SSI, you can still receive other income. How your benefits are affected depends on the type and amount of the additional income.

For SSI purposes, we consider two types of income, earned and unearned. Earned income refers to wages or self-employment income. Unearned income includes such things as Social Security benefits, unemployment insurance benefits, workers' compensation and pensions.

If your only source of income is *unearned*, we deduct \$20.00 from the total amount of that unearned income. The remainder is deducted from your base SSI check. For example, if you received \$230.00 in unearned income (e.g. a workers' compensation check), after deducting \$20.00, you have countable income of \$210.00. This means that \$210.00 would be deducted from your SSI check.

However, if you have only *earned* income, we first deduct \$20.00 from that amount. Next, we exclude an additional \$65.00. Then we deduct one-half of the remainder from your base SSI check. Here's how it works. If you have monthly-earned income of \$230.00, we would deduct \$85.00 (\$20 + \$65) which leaves a balance of \$145.00. Then we deduct one-half of \$145.00, which leaves \$72.50 in countable income for SSI purposes. This means that \$72.50 would be deducted from your base SSI check.

Keep in mind that we use gross income, not your net income, to compute the monthly amounts. And, there are some kinds of income that we do not count, such as food stamps, food you receive from churches and food kitchens and shelter you receive from most private non-profit organizations. We also exclude most home energy assistance.

If you are 65 or older, or blind or disabled and want to find out if you can get SSI, the best thing to do is to contact us. You can log onto our website, www.ssa.gov or call us toll-free at 1-800-772-1213 to ask for a copy of the booklet, *Supplementary Security Income*. It explains the eligibility requirements and what you need to bring us when you apply.

HOST FAMILY HOMES TO BE REINSTATED

After a four-year delay and millions of dollars of lost Medicaid reimbursement, the Host Family formerly called the Adult Foster Care Program, finally appears on the verge of being reinstated under the Medicaid waiver program and on having the moratorium lifted. During the moratorium period, no one was allowed to move into a host family setting. Persons who lost their host family for some reason had to go to conventional CILAs even if they chose to go to another host family. Host families that had previously provided respite services in emergencies were forbidden to do so. Amendments to the existing CILA standards have been adopted and approved by the feds. The new rules address program requirements and criteria, individuals with developmental disabilities and host family pairing procedures, provider agency and contract requirements and caregiver relief availability. At least one more hurdle remains, the development of a rate methodology. Until that is done, the old rates will stay in effect. Secretary Adams still has to formally lift the moratorium. The Host Family now becomes part of the CILA Regs (59 IL Adm. Code 115)

DD ADVISORY COUNCILS TO BE RESTRUCTURED

The Statewide Advisory Council, the Strategic Planning Committee and the eight Network Advisory Committees have continued to operate but under a doubtful mandate since the change in administration in the Executive Branch of government and the administration of the Division of Developmental Disabilities. Division Director Geoff Obrzut in an August 7, 2003 memo to the Councils, DD Providers, Trade Associations and other advocacy organizations is taking steps to reorganize the councils to allow “all interested parties to have fair and equal opportunities for input.” Steps to be taken include:

1. Attendance by the DD Director at meetings of the councils including all eight Network Advisory Councils.
2. Implementation of “standard operating procedures” for well run and organized meetings. Draft operating guidelines have been distributed to Network Advisory Councils for review, discussion and input due by September 30th.
3. Possibly replace standing committees with “workout teams” which would be short term, designed around focused issues and include representatives of all interested parties.
4. The Statewide Advisory Council continues to address the strategic plan with one meeting annually devoted to a formal review. Changes can be made, however, throughout the course of the year.

For the present, the current Statewide Advisory Council members will continue to serve. Future changes in membership are likely with elections at the Network level contemplated. Sandra Rainey & Mary Gerdes, members of Advocates United, currently serve on the Statewide Advisory Council as parent representatives. Advocates welcome

the action on Director Obrzut's part. For many of these bodies, consumer participation has waned. When they were first established, there was great participation and hope. Elections were held. People thought they were empowered to represent their constituencies and worked hard and long to reach consensus and provide input. When the Department often ignored that input, people found better things to do with their time. We hope they'll come back.

LETTER TO THE EDITOR

The federal lawsuit filed over 2 years ago and dismissed in the northern district court had a rekindling recently. On January 6th, a 3 judge panel heard arguments from Robert Farley for the plaintiffs and the Illinois Department of Human Services. It is difficult to read a great deal into this hearing other than an opinion is due by July of this year. (Ed. Note. The opinion was rendered on April 7, 2003.)

SouthStar was an active participant in this case as the five original plaintiffs were our clients. The purpose of our action was to force the state to provide services, especially small group homes within a geographic area reasonably accessible to persons with developmental disabilities and their loved ones. The trial revealed that state government had no clue as to how many of its citizens were in need of these services, nor did it seem concerned about it. Sources outside of government estimated the plaintiffs represented thousands of Illinoisans.

Many of the surviving parents of those we serve are elderly or infirm and would welcome the option of community living services in familiar surroundings for their sons and daughters along with the peace of mind they would bring. This issue and related ones continue to be tested in federal district courts where many have produced encouraging verdicts. Apparently, this matter depends solely on the court's decision as I see little chance of Illinois government ever doing the right thing on its own. This has often been the story in states where enlightened services are currently provided.

My optimism falters, however, when I read news reports like the highest courts in the land continuing to debate whether persons with mental retardation qualify for execution in capital cases. Diminished capacity, the inability to grasp the legal process and plain old humaneness, still have not moved our judicial system to what would seem an obvious conclusion. Marshaling my waning faith in and hope for humanity, I look forward to the appellate court's decision, one that has the futures of so many persons with developmental disabilities riding on it.

Pat O'Brien, Executive Director
SouthStar Services

Editor's Note: Pat, your faith, hope and advocacy were not in vain. "The Advocate" welcomes letters from its readers. The opinions expressed are not necessarily those of The Advocate or of Advocates United. Let's hear from you.

SPEAKERS FOR 2003 AT MONTHLY MEETINGS

Thanks to all of our guest speakers thus far in 2003. We really appreciate their sharing with us and their inspiration and information.

JANUARY, 2003

Planning Night—No Speaker

FEBRUARY, 2003

Ralph M. Martire, Executive Director

Jennifer Ann Holuj, Program Director

Center For Tax & Budget Accountability

MARCH, 2003

Deborah Fullilove, Network Facilitator &

Bruce Anderson, Network Representative

South Suburban Network, Division of Developmental

Disabilities, Dept. of Human Services.

Stephanie Moore & Karen Withgott, Suburban Access

Susan Carlson & Jennifer Gilmore, Service of Will, Grundy & Kankakee Counties,

Inc.

APRIL, 2003

Cindy Ganther Piser, Cornerstone Services

Laura Gardner & Paula Phillips, Sertoma Centre

Donna Brown, Kankakee County Training Center

Ivory Lowe, Executive Director & **Lynn Zona**, Southwest Community Services

Cheryl Redell, SouthStar Services

MAY, 2003

Janet Porter, South Suburban Special Recreation Assoc.

Lana Graser, Lincolnway Special Recreation Assoc.

JUNE, 2003

Beth Randell, President,

MOTHERS FROM HELL

JULY, 2003

Ronnie Barclay, Coordinator, Next Steps, DORS, DHS

DID YOU KNOW?

NEWS NOTES

GEOFF OBRZUT NAMED DD DIRECTOR

Governor Blagojevich named Geoff Obrzut to replace Geri Johnson who had been Acting Director of the Office of Developmental Disabilities since the resignation of Melissa Wright. Geoff has served as Executive Director of United Cerebral Palsy of Will County for the past nine years along with leadership positions in the State and National Association. Prior to that Geoff served in the State House of Representatives, as a

lobbyist and on the staff of the Speaker of the House Madigan among other things. By the way, he has also been a long time dues paying member of Advocates United and supporter of the biennial legislative forums. Geoff's years of experience with the Legislature and in the trenches of community service provision are real positives in any effort to turn around the State's record. Geoff has promised to speak at a future meeting of Advocates United, probably in the fall. We all wish him well in his new post. In another recent appointment, Ms. Grace Hou (pronounced "Ho") has been appointed Assistant Secretary of DHS with direct line authority over all the Divisions. We wish her well and hope she can be a guest speaker.

SURREPTITIOUS AMENDMENTS TO SB319 WEAKEN STATE PUBLIC HEALTH INSPECTION RULES

Advocates United members voted at the July meeting to ask Governor Blagojevich to veto amendments to SB 319 which would eliminate the requirement that the Department of Public Health surveyors actually visit a nursing home to investigate complaints of abuse and neglect. Another amendment would extend the time allowed to conduct investigations by at least 30 days in all cases and indefinitely for most. These amendments were quietly inserted by the House sponsor of the Senate Bill unbeknownst to the Senate sponsor at the behest of a lobbyist for the Illinois Health Care Association, a trade association for the nursing home industry. Opposed by both the Illinois Department of Aging and the Illinois Department of Public Health, these provisions would adversely affect many of our members who have adult children, family members or wards living in nursing homes or Intermediate Care Facilities for the Developmentally Disabled, both community based and State operated. Now when one of the approximately 6000 annual complaints of abuse or neglect are received, state inspectors make unannounced visits to look into the allegations. The original bill, which began as a change of the Nursing Home Care Act, has some good provisions which should be retained. One of these allowed nursing home employees to sue their employers if they had suffered retaliation for filing an abuse/neglect complaint. Another is an expansion of what constitutes abuse and neglect. We are asking Governor Blagojevich to use his amendatory veto power to strike the language changing Section 702 of the Nursing Home Care Act. Concerned members should also write the Governor.

SB 1543 CREATES NURSING HOME RESIDENT SEXUAL ASSAULT/DEATH REVIEW TEAMS.

Modeled on the Child Death Review Teams advising the Department of Children & Family Services, SB 1543 would create Independent nursing home (including community ICFsDD and State Developmental Centers) resident sexual assault /death review teams to advise the Department of Public Health, the licensing and inspecting agency. Each team would include medical professionals, law enforcement professionals, experts in the mental illness and developmental disabilities fields and nursing home experts. Based on these independent reviews, the teams would recommend changes in policies and procedures for IDPH, nursing homes and other agencies in order to reduce the appalling incidence of sexual assaults and avoidable deaths among residents. Advocates United members voted to support this.

FOCUS GROUPS ON FUTURE RESIDENTIAL

A series of focus groups about “The Future Configuration of Residential Services in Illinois” are being held in July and August under the sponsorship of the Illinois Planning Council on Developmental Disabilities. Sheila Romano, Director of the Council, contacted Advocates United asking for our participation in the series of what are being called “listening sessions and interviews” aimed at “gaining a thorough understanding of the concerns about, and obstacles to moving the Illinois residential services system toward smaller, more integrated options.”

Not intended as a debate about the merits of the various types of residential options, the focus groups are being asked to voice their issues and concerns from those most affected by possible future changes and stakeholder points of view about what it would take in Illinois to increase choices for smaller, more integrated community options. Dan & Joyce Hecht, Tom Ryan, Sandra Rainey, Dolores Keipert and Carol Bruggeman attended one group representing Advocates United. The advanced agenda requested suggestions on the future role of State Operated Developmental Centers, large ICFsDD serving more than 16 people of which there are 50 in Illinois and ICFsDD serving between 8 and 15 individuals. Input was requested on how these settings could be downsized and reduced and the barriers to that. The study is being done by the National Association of State Developmental Disabilities Directors of Services under contract with the Planning Council. The same organization is also conducting a study on ways to increase Medicaid reimbursement for currently provided services for people with developmental disabilities. According to Dave Braddock in the recent publication, “Disability At The Dawn Of The 21st Century And The State Of The States,” Illinois is failing to capture Medicaid matching funds for \$290,000 or 24% of the money currently being spent. During FY’02, \$115 million was spent on grants for adult services for which no matching funds were sought. Another \$71 million was spent on largely childrens’ services, home and family support, respite and family assistance. The majority of the children served under these programs are not on Medicaid as their parents’ income exceeds Medicaid eligibility standards. Many are in that growing group of citizens in the U.S. who are too poor to afford health insurance but not poor enough to qualify for Medicaid. Nevertheless, if more of the eligible programs in Illinois could be brought under Medicaid, the matching dollars could be used to finance much needed expansion. Why Illinois has not done this as have other states remains a mystery. Maybe the study can shed some light on it that since it’s one of the principal reasons Illinois ranks near the bottom nationally.