

## LINCOLN DEVELOPMENTAL CENTER IN TROUBLE

The Lincoln Developmental Center (LDC) operated by the State Of Illinois Department Of Human Services, first opened its doors in 1877 in the town of Lincoln, 30 miles north of Springfield. Then known as the "Lincoln State School And Colony", it had been moved there because of overcrowding from an earlier foundation in 1865 in Jacksonville, Illinois known as the "Illinois Asylum For Feebleminded Children." Home to about 5,000 residents at its peak in 1956, LDC recently served 378 residents down from 437 in 1998. Several years ago, a large part of the facility was converted into a prison. Lincoln DC was accredited by The Council and The Commission for the Accreditation of Rehabilitation Facilities (CARF), which are national accrediting bodies.

## DPH CITES PROBLEMS/DHS PROPOSES CURE

Yet, during late summer and fall, a series of unannounced visits from the Illinois Department of Public Health which licenses, certifies and investigates allegations of abuse and neglect at State facilities, has generated 89 pages of violation citations mostly having to do with Facility Staffing, Client Protection and Active Treatment. In fact, during the period FY97-FY00, LDC had the most citations among all the state operated facilities in the latter two areas. This is only the most recent manifestation of a long history of problems at LDC going back to at least the 1970's. Now the facility faces Medicaid decertification which will mean the loss of \$17 million in federal reimbursement, half of LDC's budget. The State DHS Office of Developmental Disabilities, to stave off decertification, originally announced immediate movement of 90 LDC residents to 3 Chicago Area State facilities in an effort to bolster the LDC staff/client ratio. Howe (Tinley Park) and Ludeman (Park Forest) will each take thirty-five people with Shapiro (Kankakee) taking the other 20. The receiving facilities have been told to step up placement efforts of their own into community CILAs. DHS officials say they have enough funding this year to place 150 individuals into currently unfunded CILA vacancies. This is supposed to help LDC since no staff will be transferred with the residents. Officials say the people being transferred have "ties" to the Chicago area. Veteran observers of State operations predict that first on the list of "movers" will invariably be people who are wards of the Office of State Guardian (OSG) with no active family members involved. Some observers wonder why the State chose to move people to the Chicago area and displace current residents of Chicago area facilities into the Chicago networks where there are virtually no ICFDD or CILA vacancies. Why not consider placements into the 149 ICFDD vacancies DHS says are available in Southern Illinois counties?

State officials reportedly have said that placements don't have to be confined to the Metro South Network area since many of the Lincoln residents to be transferred come from all over the State and others are unlinked to families.

Others question the wisdom of transferring residents from LDC to improve staff/client ratios there to other state facilities which have equally poor or even worse staff/client ratios. Doesn't this also put these facilities in peril of decertification?

Meanwhile, as part of the movement process, meetings were held with parents and involved family members of Lincoln residents. At the meeting at Lincoln, one parent told THE ADVOCATE that State officials recounted the background and history of Lincoln's problems and explained about the proposed moves. They also were reported to have implied that the parents/family members shared the blame for Lincoln's problems since they had opposed placement of their family members into community settings. Other parents invited to meetings held at the 3 receiving facilities say there was no mention of this, rather they found the meetings informative even though they had mixed feelings about uprooting their family members. People were given tours of the receiving facilities. Transportation and lunch were provided.

#### THREAT OF CLOSURE RESISTED

Some Statewide advocacy groups are lobbying Legislators and the Governor's Office to close down Lincoln. They cite a long history of seemingly intractable problems and recent instances of neglect and abuse. In November, 1998, a resident died of suffocation after being held in restraint for 45 minutes by 5 staff. In November, 2000, a resident drove off in a stolen semi-trailer truck toward Bloomington. In January, 2001, a resident was left unsupervised in a bathtub and nearly drowned. Later that March, a resident with pica behavior (eating inedibles), nearly died when he ingested pills taken from an employee's purse. The following July, another individual did the same thing, went into respiratory arrest and died. In March there was the incident of a resident being allegedly choked with a sheet by an LPN while in restraints. All this and more is detailed in a nine page briefing paper provided to parents and family members at the aforementioned meetings held by the DHS Central Office Staff. Also described in detail are the prodigious training, technical assistance, policy and procedures changes and management changes at Lincoln that have been made over the past 10 years. Seemingly, nothing has worked.

Despite all this, many parents say they are satisfied with services at Lincoln and are calling for the State to keep that facility open and fully funded. They say their family members are doing well at Lincoln and that they don't know where they will go for equivalent services. Many suspect that the real agenda of the State is to create a situation so as to be able to give reasons for closing the facility. Further fueling suspicions is the news that 105 not 90 people will be moved out. Meanwhile, the Lincoln/Logan Chamber Of Commerce representing the businessmen of the area are encouraging their members to write to Governor Ryan, State Representative Jonathon Wright and State Senator Claude

“Bud” Stone opposing the closure of LDC which provides jobs and pumps \$34 million into the local economy. Lincoln Mayor Beth Davis is working at the local level and with representatives of AFSCME to organize support to keep the facility’s funding in place and the current number of residents and staff intact. On the other side, people without services and community agencies needing additional funding are being urged by advocates for closure to write to the Governor and their legislators to close Lincoln and use the money to serve more community people. According to one report, the Statewide Advisory Committee is recommending that the money supposedly saved by closing Lincoln could be used to make up the State’s budget shortfall. That is what was done when Dixon closed.

## WHERE WILL PEOPLE GO?

Central to this discussion are several vexing questions which no one seems to be addressing. If Lincoln closes precipitously, where will people go? Most of the neglect and abuse incidents seem to involve individuals who have very challenging behaviors such as PICA or serious medical problems. The current CILA rate methodology would not support a suitable community program for these individuals, e.g. one hour of nursing care per month. Some individuals are in state facilities because community agencies were unable to provide a program for them with the resources available. Others are there because no community agency would accept them. Add to this that Statewide only 30 moves into CILA openings are being allowed, 80% of which are vacancies created by the death, discharge, withdrawal or movement of current CILA residents. Given that over 28,000 adult individuals with DD live with caregivers over the age of 60 in Illinois, there is a constant demand for services due to emergencies. According to a recent report, there are only 18 ICFDD vacancies in the Chicago area network where 65% of Illinois citizens live. Few if any of these will accept people with severe problems. Funded CILA vacancies are rare and are reserved by Central Office of DHS for “emergencies only.” Now we have the additional pressure on the already overburdened system by placement of 90 individuals out of Chicago Metro Area state facilities to accommodate Lincoln transfers.

## STILL NO PLAN

There have been laudable efforts by the Office of DD to put forward a Strategic Plan. This was done with orders from the Governor’s Office that it would contain no numbers of people waiting for services and no new funding. Any real plan must face up to the need exacerbated by 25 years of neglect and inadequate financing. With no plan, the State continues its erratic course of crisis (mis)management hurting a lot of people. No wonder despair of change any other way leads to recourse to the federal courts. N.S. Worthy

Back to top

## BOUDREAU V. RYAN PLAINTIFFS SEEK CLASS ACTION

In a series of hearings being held since mid November in Federal District Court, attorneys for the plaintiffs in Boudreau v. Ryan are arguing before Federal Judge Thomas Grady seeking designation as a class action. The suit requests that the State provide Medicaid funded developmental disabilities services, particularly residential services (ICFsDD & CILA) and day and vocational services to adults with developmental disabilities who have been found eligible, have requested services from the State and have not received them within a reasonable time as the plaintiffs say are required by federal statutes governing the Medicaid program. Named plaintiffs have been waiting for services, some for years. The University Of Illinois national, longitudinal study estimates that there are nearly 29,000 adults with developmental disabilities living in Illinois with caregivers over the age of 60. Thousands more live with caregivers under 60 have graduated from special education only to sit home waiting for services year after year.

## DEFENDANTS CLAIM EVERYONE SERVED

Attorneys for the State, on the contrary, claim the State officials they represent “...know of no person with developmental disabilities or mental retardation in Illinois who is eligible and is not receiving services.” Not knowing and apparently not wanting to know, some of these same State officials testified and lobbied against the passage of the “Waiting List Bill” in the past three biennial sessions of the Legislature. Attorneys for the plaintiffs are presenting evidence and calling on witnesses to testify as to the facts of the situation in Illinois, arguing before Judge Grady that there is a Statewide dearth of services to eligible people based on a deliberate State policy to ignore anyone who is not an emergency.

## STATE’S ATTORNEYS PUSH ICFDD PLACEMENTS

The state’s lawyers from Hinshaw & Culbertson contend that there is no basis for a class action. They say there are plenty of ICFDD vacancies to accommodate all of the plaintiffs and anyone else seeking residential placement. They say the state is only mandated to provide ICFDD services, not Community Integrated Living Arrangements (CILA) is a program covered under the Medicaid Waiver. The State claims that the Waiver is not mandated so the State decides who gets Waiver services. Illinois has

deliberately limited waiver “slots” since the Waiver was first introduced at the federal level. In fact, Illinois, as usual, ranks near the bottom in the U.S. in the use of the Waiver Program. The attorneys for the State argue that the parents of the plaintiffs are just being too picky and should accept whatever ICFDD vacancies are offered them. Recent testimony, however, revealed that there were only 18 ICFDD vacancies in the 9 county Chicago Metro Area. It was revealed that most of the approximately 169 ICFDD vacancies statewide are located in the southern extremity of the State. Lawyers for the State contended that this should not matter, even if it means parents have to drive 4 or 5 hours to see their family member. They denied that continued involvement with their families was necessary for people with developmental disabilities. Parents told us they were outraged. Fortunately, expert testimony presented by the plaintiffs contradicted this.

Meanwhile, a number of community agencies and service coordination agencies testified to having extensive waiting lists of hundreds of eligible people who had not received services.

#### STATE CLOSING MANDATED ICFsDD,

State officials and providers testified that the stock of ICFDD beds –the only mandated service– was actually being reduced by a conscious policy of the State. Some providers said they were denied permission to open up additional ICFsDD. State officials claimed credit for closing down existing ICFsDD and said they had a long range plan to reduce them still further including the conversion to CILAs of 1000 ICFsDD 16 or fewer “beds” by “the State’s largest provider.” State officials claimed that all ICFsDD were too “institutional” and “regimented” when compared to CILAs even including in their condemnation the 4 and 6 bed ICFsDD. So what we have is the State saying only ICFsDD are mandated and they are in the process of closing them in favor of CILAs which are not mandated and which only people who are emergencies can have. Does this sound like another version of the Florida debacle where the State legislature tried to evade responsibility for serving eligible people waiting for services by seeking to abolish the whole ICFDD Program from the State Medicaid coverage? They were only going to keep their non-mandated Waiver Program. Later they found out that to have the Waiver, you must have the ICFDD Program first. In a surprise move last week, attorneys for the plaintiffs filed for a Temporary Restraining Order preventing the State from blocking providers who want to develop ICFsDD in the future. The State is crying foul while at the same time it has issued over 30 CILAs licenses to new unproven providers just in the South Suburban Network just in the last four years. They say it provides healthy competition for existing providers. Waiver CILAs are not mandated so these new, unproven providers are competing primarily for emergencies and State facility discharges, among the most difficult people to serve, a recipe for disaster. Back in Federal District Court, Judge Grady is expected to rule soon on the Class Action designation. Stay tuned. NSW

Back to top

## WHAT A DIFFERENCE A CAR MAKES

President – Tom Ryan

When my developmentally disabled son is home for an overnight visit, I usually find myself driving him back to his nearby home on Sunday evening. Always, as we turn the corner approaching his house, he comments as he sees the cars in the parking area, as to which staff members are on duty. He is always more excited and enthusiastic about returning to “his house” when he can anticipate being greeted by great caregivers he has known for years.

I think I have just shared with you what “staff turnover” of the caregivers of our sons and daughters is all about. Regardless of the level of handicap (and even for “normal people”), there is more of a comfort level and feeling of security when we interact with people we know-especially when we are in a vulnerable situation. We are fortunate that our son can verbalize his feelings in this regard-but I am confident he reflects the feelings, securities and insecurities of the less verbal.

The recent \$1.00 per hour raise to front line staff funded by the Legislature was a great start. I view this as a big step in attracting and retaining quality caregivers. As advocates, we need to take credit for the victory and continue thanking our legislators for listening. I really feel that without “grassroots” advocacy efforts of all of us, this would have not happened. Much more needs to be done! More compensation, more recognition, better training and the development of a real professional career path for direct care staff are issues. We join with progressive service providers in our advocacy efforts.

During the New Year, why don't you and I thank and recognize those caregivers that mean so much to our respective families. A greeting card and/or a “thank you” comment can mean so much to these important people in the lives of our loved ones.

Back to top

## ELECTION OF OFFICERS FOR 2002

The members at the December 11th Monthly Meeting elected new officers for 2002. They are Dan Hecht, President; Warren Brown, Vice President; Richard Bell, Secretary & Dolores Keipert, Treasurer. Members-At-Large are Tom Ryan, Mary Mayer & Fred Boland. For 2002, Tom Ryan will chair the Membership Committee, Dick Bell, the Legislative Committee, Barbara Olson, the Special Events Committee & Warren Brown, and the Publicity Committee. All committee chairpersons are looking for members. Other committees will have chairs appointed soon. Volunteers needed.

[Back to top](#)

## 10th ANNIVERSARY GUEST LEGISLATORS SPEAK AT AU

### LEGISLATIVE FORUMS

Advocates United has sponsored 5 biennial legislative forums during our 10-year history. The following is our HONOR ROLE of the legislators who graced us with their presence with the number of forums attended after their names.

Rep. Harold Murphy, (D-30), 1

\*Rep . Terry Stezco, (D), 1

\*Rep. Larry Wennland, (R), 2

\*Rep. Stephen Spangler, (R), 2

Rep. Brent Hassert, (R-83), 4

Rep. Phil Novak, (D- 85), 5

Rep. Jack McGuire, (D-86), 3

\*Rep. Ed Zabrocki, (R), 1

Rep. James Meyer, (R-82), 2

Sen. William F. Mahar, (R-19), 3

\*Sen. Aldo DeAngelis, (R), 1

Sen. Debbie Halvorson, (D-40), 3

Sen. Edward Petka, (R-42), 1

Rep. Maggie Crotty, (D-35), 3

Rep. Renee' Kosel, (R-38) 3

Rep. Mary K. O'Brien, (D-75), 2

\*Rep. Michael Giglio, (D), 2

Rep. George Scully, (D-80 ), 2

Rep. Kevin McCarthy, (D-37), 2

Rep. Kevin Brosnahan, (D-36), 1

Rep. Thomas Dart, (D-28), 1

Rep. Anne Zickus, (R-48), 1

Sen. Larry Walsh, (D-43), 1

Sen. Emil Jones, (D-14), 3

Sen. Patrick Welch, (D-38), 2

Sen. Patrick O'Malley, (R-18), 2

Sen. Christine Radogno, (R-24), 1

Rep. Eileen Lyons, (R-47), 1

Gubernatorial Candidate

Glenn Poshard (D)

Lieutenant-Governor Candidate

Mary Lou Kearns (D)

Lieutenant Governor

Corrine Wood (R)

\* no longer in Legislature

Plus many unsuccessful candidates for election to the Illinois General Assembly. Thanks to all and we hope to see you again at the -

SIXTH BIENNIAL LEGISLATIVE FORUM, SATURDAY, SEPTEMBER 7TH, 2002  
AT THE ORLAND PARK CIVIC CENTER

12:30 TO 3:30 P.M. IT WILL BE THE BEST EVER!

Back to top

Bell's Brief's

By: Dick Bell

#### LINCOLN WOES DIVIDE ADVOCATES

Someone once defined a "Firing Squad Of Liberals" as a group of people with guns forming a circle facing in." The same could be said of many people and organizations claiming to be advocates for people with developmental disabilities. Rather than pooling their strength to achieve agreed upon, common objectives, they dissipate them by attacking each other and accusing each other of mistaken thinking and bad motives. Recent events at the Lincoln Developmental Center have sent people to their soapboxes—I should talk—calling for closure of Lincoln on the one hand or the maintenance of the large facility option on the other. At the November meeting of Advocates United, one of our members presented a draft letter to the State signed by a group of advocacy organizations urging the State to continue to maintain the ICFsDD option including larger facilities. A motion was made to add our name to the supporter organizations. During the ensuing discussion, I had flashbacks to visits I had made years before to Dixon in the bad old days—six men with profound mental retardation lying naked together on black plastic mats on the floor with flies crawling over them while the staff chatted in the glass enclosed nursing station, large rooms in cottages barren except for scattered and shapeless blue vinyl foam rubber "furniture" and blaring TVs bolted to the ceiling while a dozen young male "inmates" gathered around the only staff member present, a pretty young woman wearing an ensemble better suited to the beach, who was obviously flirting with them. Fortunately, no one touched her, otherwise they would be written up and put on a program. I recall a barren room with seatless toilets sprouting up at intervals without any stalls for privacy and with adult people with developmental disabilities in diapers being given lots of pop to drink so they could be toilet trained in public. My mind went back to the time I was in charge of two units of 100 people each, 10 to a house, at the Waukegan Developmental Center (now Kiley) when a staff member "lost it" in the

middle of the night and beat a resident so badly he died the next day from internal injuries. Hopefully, those days are gone forever. Though I am no fan of institutional care, I voted to add Advocates United's name to the petition. The wording of the petition called for respecting peoples' choices and didn't accuse others of bad faith or ignorance. After all, the basis for Advocates United is affirming people's right to choose what they think is best for them and providing them with the best information available in making their choices. Despite my dislike of institutional programs wherever they are, I decided I didn't want to join the firing squad.

But there were other reasons too. The principal and overriding one is that the advocates of closure are shooting at the wrong targets. The problem with the service system in Illinois, which has resulted in Illinois abysmally low ranking among the states in virtually every measure, is not people defending large facilities. The problem has been the residents of the Governor's mansion who have ignored and neglected persons with developmental disabilities for over two decades. You doubt this? Consider, for example, the attitude of the administration to the waiting list bill. They have blocked it from even being called to a vote. They don't want to know. The data shows most other states much better off.

Equip For Equality argues that Lincoln should be closed because it is incapable of providing a program and a safe environment for the residents. They were there. They investigated. I was not. What I do know is that the State of Illinois has one of the lowest staff/client ratios in the nation in its state facilities. That public policy is set by the Governor primarily and his Bureau Of The Budget. Because of this, at least three other state facilities are in danger of decertification as well. But instead of adding resources to Lincoln, they ship out some of the residents to other facilities, which also have poor staff/client ratios. It will come as no surprise to anyone if I tell you that, given the rates paid to community providers and wages to front line workers in the community, staff/client ratios and staff vacancies and turnovers are rife in the community as well. Closing Lincoln won't help this.

Some community advocates in favor of closure invoke the old siren song of getting the money from the expensive state facility care and serving a lot more people in the cheaper community programs. What they fail to address is the lack of staffing in community programs compared to state facilities with their doctors, nurses, dentists, therapists, psychologists and the like that some people need. Community CILA rates allow for one hour of nursing care per month compared to a Howe with its nurses and LPNs providing in excess of 14 hours per resident per month. When Governor Edgar was faced with budget problems, he cut dental, podiatry, vision and hearing services to Medicaid community residents. State facility residents continued to receive those services. Instead of advocating for comparably staffed programs in the community that people with relatives in State facilities might consider, we find ourselves advocating for "cheaper" programs than the ones that are already on the edge due to lack of funding. At the risk of repeating myself "ad nauseam" I say to such advocates that cutting the same old pie in different size pieces leaves everyone worse off. We need a bigger pie. We know, that as the State budget has grown over the years, the share people with developmental

disabilities get grows proportionately smaller. Consider this year's budget where the \$1.00 per hour wage increase for front line workers came at the expense of virtually no expansion of any programs, the worst year in the past twenty. The prospect of the money following the person from the State facility to the community is a fantasy. It didn't happen when Dixon closed. People were doubled up "temporarily" in the other State facilities and the Governor took the money to plug holes in his budget. It wasn't even supposed to happen in the case of Kiley. The planning document showed a savings from closure going back into the State treasury. Downsizing proposals don't begin with up front funding to develop comparable community based services for people to move into. They always begin with people moving to existing vacancies in the community, some of which are vacant for good reason. Then the savings vanish into next year's budget "priorities."

[Back to top](#)

Transition Talk

By: Mary Mayer

WHAT TO EXPECT AT A

TRANSITION PLANNING MEETING

Do you want to know what happens at a transition planning meeting, who attends, what is discussed, as well as some common misconceptions regarding post high school planning? Read on.

First of all, why do transition planning at all? The transition service requirement of the IDEA provides a variety of valuable opportunities such as:

à Assisting students and families to think about the future and consider what they want to do after high school.

à Allowing time for students, families and school personnel to plan together on how to make high school experiences relate directly to the students' and parents' desired outcomes.

à Assisting students and families to connect with the resources they will need both during and after high school.

à Increasing the likelihood that students will be successful when they exit school.

It is important to recognize, that as a student grows and changes, so does their interest in school and post school outcomes. Therefore, flexibility is a major component of all aspects of transition planning, as well as the importance of planning ahead.

At age 14, we begin to initially address transitioning and the need to start completing applications for sheltered employment or supported employment (if this is the post high school goal) due to the extremely long waiting lists at community agencies. Many parents do not realize the need for this at such a young age but it is imperative if we are to hope for no interruption in services once a student graduates from high school

As a student approaches the age of 18, more emphasis is placed on guardianship, applying for SSI, Medicaid, etc. Referrals to the Office Of Rehabilitation Services (ORS) and independent service coordination agencies such as Suburban Access and Service Of Will, Grundy & Kankakee Counties, Inc. are discussed at this time as well. The “age of majority”

is also discussed which sometimes can be quite confusing to parents. Beginning at least one year before the student reaches the age of majority under state law (18 years old in Illinois), a statement that the child has been informed of his/her rights under this title is shared. Many parents do not realize that when their child turns 18, the parents are no longer considered the legal guardians. Once they turn 18, the child is considered in the eyes of the State, their own legal guardian unless the parents go through a formal court procedure to obtain and establish themselves as guardians, if needed.

As mentioned earlier, age 14 is not too early to begin applying for adult vocational services waiting lists which are very long if you wish a smooth transition from high school into an adult service without waiting at home several years for an opening as so many have to do. Funding is needed in order for an individual to work within a sheltered workshop or vocational program after high school as well as for various types of supported living arrangements and home based funding resources. In Illinois, such funding is not easily obtained so early application is advisable. This can all be discussed during transition planning sessions.

A student can and should apply for a Medicaid through the local office of the Department of Human Services once they reach the age of 18 regardless of their parents' or guardians' income.

Who should be there at the first transition planning meeting? My suggested list would include the following:

à Parents

à The student, if appropriate

à Special education teacher

à Regular education teacher (if the student is participating in the regular educational environment.)

à The work study coordinator, transition facilitator and prevocational coordinator

à Adult service agency representatives

Representatives of State agencies such as the Office Of Rehabilitation Services should be invited.

**REMEMBER: IT'S NEVER TOO EARLY TO START THE TRANSITION PLANNING PROCESS !!**

Back to top

**ADVOCATES UNITED**

**CELEBRATES ITS TENTH**

**ANNIVERSARY IN FEBRUARY, 2002**

**OUR HISTORY**

In the month of February, 1992, a small group of people met at the Holiday Inn in Matteson, Illinois and decided to form a new organization. The people were people with disabilities, parents and family members of people with disabilities, a few professionals and service providers and people of good will. Represented were people having family members in State facilities, in community ICFsDD both large and small, in community CILAs, in children's facilities, or living at home with family members of all ages. After a lot of discussion, they chose the name "Advocates United" because it seemed to express best their belief that all people who supported people with developmental disabilities ought to be welcome and work together regardless of their various preferences on what should be done. Respect for peoples' choices was paramount rather than adherence to a particular disability or programming type. An equally strong commitment was to provide the best and most comprehensive information available for the members who then should be trusted to make up their own minds. Where the members agreed, the organization would advocate for change such as with the waiting list issue or decent wages for community front line workers. Where the members did not agree, they agreed not to take an organizational stand but to respect each member's opinion and to provide a forum for the free and open expression of differing opinions. Since February of 1992, Advocates United has met every month except September 11, 2001 out of respect for those who died in the terrorist attacks. Membership has gradually grown over the years. Advocates United receives no government or foundation funding of any sort, only the dues and donations of our members. This way we believe we can advocate for what our members chose to support without being dictated to by any funding source. Anyone interested in joining can call 815-741-0800 and request information.

#### THANKS TO ALL OF OUR GUEST SPEAKERS

1992

Terry Varnet, MSW, JD; Spain, Spain & Varnet

Jess McDonald, Dir. Dept. of Mental Health & DD

1993

Lynda Atherton, Parent Advocate

Al Smith, Ill. State Board Of Education

Carl Hamilton, DORS, Home Services Program

George Cutright, Social Security Administration

Sharon Nemeth, Dignity Group

Peter Lennon, Consumer Owned/Controlled Housing

Lynn Elwood, Will/Grundy CIL

Peg Redding, Evelyn Barney & Sheila Romano from

Independent Living Opportunities

1994

Kelly Cunningham, Office of the Governor

Meeting with Race Davies, House Republican Staff

Meeting with Joan Walters, Director, Bureau of the Budget

Sara Straney, Ill. Planning Council

1995

Mary Mayer & Nora Paape, Transition Planning

Ann Hilton Fisher, J.D., Legal Assistance Foundation

Tony Paulauski, ARC of Illinois

Jean Fox, Office Of Inspector General

Lynn Handy, IDMH/DD, Acting Director

Audrey McCrimmon, Director, DORS

Robin Jones, U. of I. Dept. on Disability & Human Dev.

Lydia Glasson, J.D., Equip For Equality

Ann Patla, IDMH/DD, Director

Frank Bogard, 1st Named Plaintiff, Bogard Class Action

Wallace Winter, J.D, Legal Assistance Foundation

Pat Curtis, IDMH/DD, Kiley Transition Coordinator

Roberta Lynch, Deputy Director, AFSCME

Tia Nelis, President, People First of Illinois

Hazel Shapen, President, Howe ARC

Shawn Jeffers, Associate Director, DMH/DD

1996

Pat Curtis, Inspector General

Patrick Rodgers, Social Security Administration

Gerry Beagles, Network Coordinator, South Suburban

Rep. Stephen Spangler, (R-75)

Rep. Phil Novak, (D-85)

Kerry Lacko, Gov's Task Force, Human Service Reform

Laura Sakas, Managing Attorney, Office of St. Guardian

Helen Godlewski, Guardianship Managing Administrator

1997

Meeting With DHS Secretary Howard Peters III

Gerry Beagles, Chicago Network Coordinator

Sandy Thurston Ryan, Ill Planning Council

Jayne Levin-Murial, J.D., Spain, Spain & Varnet

Ted Burke, Early Intervention Resource Spec, Starnet

Richard Hemp, Proj. Dir., Nat. Study of Public Spending for DD, Univ. of Illinois

Jennifer Light, J.D, Staff Attorney, EI Serv. In Illinois

1998

Senator William F. Mahar, (R-19)

Representative Jack McGuire, (D-86)

Kathy Muniz, Facility Director, Howe Dev. Center

Ira Collins, Facility Director, Shapiro Dev. Center

David Decker, Facility Director, Ludeman Dev. Ctr.

Rep. Mary Kay O'Brien, (D-75)

John Budny, Director, Office Of DD

Jan Miller, DORS, Supported Employment Specialist

Cindy Lapicki, Dir. Of Rehab, Cornerstone

Cindy Ginther-Piser, Coord. Of Comm. Employment, Cornerstone

Robin Mirtes, Community Placement Service Mgr., St. Coletta's of Illinois

Melissa Gonda, Dir. Of Employment Services, Sertoma

Kevin Steelman, Budget Director, DHS

Rep. Louis Lang (D-16)

1999

Senator Thomas Walsh (R-22)

Carl LaMell, President & CEO, Clearbrook Center

Scott Kimmel, DHS, Rates Unit

Melissa Wright, Associate Dir. For DD, DHS

Bob Scanlan, Chic. Metro Area Network Coordinator

Sheila Romano, Exec. Dir., Ill. Planning Council

Rep. Renee' Kosel (R-38)

Gary Miller, Director, Ill. Guardianship & Advocacy

2000

Odell Thompson, Inspector General, DHS

Morris Fred, Illinois Guardianship Reform Project

Carl Suter, Associate Director, Office of Rehab. Services

Sen. Patrick J. O'Malley (R-18)

Art Dykstra, President & CEO, Trinity Services, Inc

Elaine Hoff, Policy Advisor On Disability Rights,

Attorney General's Office

2001

Susan Ewald, Director, Conference of Women Legislators (COWL)

Robert H. Farley, Jr. J.D., Plaintiff's Counsel For Boudreau V. Ryan

Rep. Robert Ryan (D-79)

Rep. James D. Brosnahan (D-36), Chair, House Committee on the Disabled Community

Nancy DeMarco, Director, Ill. G & A Commission

Ron Wampler, Chief, Developmental Disabilities Section, IDPH

Michele Piel, Olmstead Coordinator, State of Illinois

Kathy Muniz, Assistant Associate Director, Office of DD, DHS.

Meeting with Linda Renee' Baker, Secretary of DHS

2002

Jeri Johnson, Assistant Associate Dir, Office of DD

**WE THANK ALL THESE GUEST SPEAKERS FROM THE PAST 10 YEARS WHO HAVE KEPT OUR MEMBERS SO WELL INFORMED. THANKS ALSO TO ALL THE LEGISLATORS AND CANDIDATES WHO ATTENDED OUR FIVE LEGISLATIVE FORUMS (SEE PAGE 2). "THE INFORMED CONSUMER CHOOSES BEST."**

Back to top

Early Intervention

Update

By: Dieter Burr

Editor's Note: Correspondent Burr has been on the go lately and hard to reach for comment on the EI scene. Just the other day we finally ran him to earth browsing the Route 66 Museum and truck stop on his way to Springfield.

THE ADVOCATE: Deiter, at the end of our last interview, you said you were concerned, "scared" was the word used...about problems of "provider recruitment" and "quality in the system". You promised to elucidate. What's scaring you, Deiter?

BURR: Here's what scares me. The State is mandating EI services and then they are bringing in new providers without any track record in the field and presenting these providers to parents as qualified to work with their children. You've got OTs coming out of geriatric work that have never worked with toddlers. If they get any additional training, they're getting it on their own, not because it's required by the State. Then you have many service coordinators with a B.A. in a human services field but no experience yet families are given the impression that they are experts.

THE ADVOCATE: What else worries you about the system, Deiter? Your brows are knitted. You must be worrying.

BURR: We're not getting a coordinated service system which meets the needs of families. For example, families with insurance are being driven out of the system because of the \$200.00 per month family liability. Instead of paying that to the State, they just use the therapists their insurance pays for. There's then no coordination among therapists, no transitioning into the school system and we're back to the old therapist based system. The net effect, which some people think is the State's hidden agenda, is to drive out these people thus reducing the EI program to only people on Medicaid and allowing the State to cut the EI budget. Then the onus will fall on the school district and the community when the children turn three having missed crucial services. No wonder my brows are knitted.

THE ADVOCATE: Deiter, you're always so dour. You went to a Springfield meeting recently with the EI Statewide Council and the new EI Director Kopel at DHS. Any good news?

BURR: There were a couple of positive developments. They've started to focus some on the credentials of providers entering the system and are talking about some more intensive educational requirements specific to infants. They also are recommending that assistants will now have to have hands on supervision of a fully licensed therapist when working with the children. I was also pleased that there seems to be more interest in open communication and input. Before, if you went to the meeting, you could only sit there mutely listening. Nobody seemed to want any input. Now they are actively asking for it. That's a good thing because there's a lot of good experience sitting there to be used to help better the system.

THE ADVOCATE: It's hard to picture you mute, Deiter and we'd like to talk more but we're out of column space. Next issue will you tell us about what other states are doing?

Back to top

## LETTERS TO THE EDITOR

### THE DOWNSIDE OF FUNDRAISING

Dear Advocate:

There is a long history of not-for-profits struggling financially while recent events make the future seem even more daunting. Continuing the good fight, boards and management hatch new schemes that will hopefully launch their organizations into the good times. Especially in Illinois, fund raising is a condition of a 501(c)(3)'s survival, an inescapable given. From Bingo to auctions and dinners, to golf tournaments and fashion shows, to Christmas sales and celebrity nights where your ticket entitles you to rub elbows with a Michael Jackson look-a-like (imagine the thrill). The list is endless. And all the while, pounding home the theme....that the donor's generosity benefits the individuals receiving the organizations' services.

While these dollars are precious and not easily replaced given our funding system, there is a significant downside to fundraising. This includes the beneficiary, our client, becoming the publicized object of charity. Serving people with disabilities, this is not a message consonant with inclusion, integration and equal rights. A big part of our mission is to further the social acceptance of our clients in housing, employment and all facets of

community life. This desired perception is surely undermined by begging for money to help these typically perceived “unfortunate souls.” While we seek respect for our people, we may unintentionally evoke sympathy, even pity. When medically disabled people are admitted to the hospital, they are never told, “We will have to raffle a few more cars before we can do your heart transplant.” These folks rely on a different system—private and government insurance—to fund their care. We may have to depend on a bake sale. Another liability of our system is that the resources required to execute complex fundraising schemes distract us from our true mission. Too much time concerned with raising money and not enough time devoted to directly improving the lives of our people, exacts its toll. How many agencies have you known whose fundraising and public relations effectiveness far surpass those of their client services? This “tail wagging the dog” puts an agency’s credibility and its very reason for being into question.

Realizing there is no easy solution to our dilemma, I too, continue to play the fundraising game. Until government gets more generous or another funding mechanism is developed, our present tradition will not only endure, but will become even more elaborate, demeaning and time consuming. Have you heard the one about the “Night At The Races” that features dinner, open bar, dancing, a jockey fashion show and the finale, the grand prize raffle of a horse, all while images of your disabled clients are beamed on the jumbotron screen high above the tote board. Call it festive or call it crass, but hey, in the world of social services, it’s a living.

Pat O’Brien

South Star Services

Editor’s Note: Letters to the editor printed in THE ADVOCATE reflect the views of the author and not necessarily those of Advocates United or its members. We welcome responses on this or other subjects of interest to our readers.

[Back to top](#)

## WAITING FOR THE WAITING LIST

By Tom Ryan

November 28, 2001 —a great day in our organization’s annuals! On that day, a committee of four, Dan Hecht, Dolores Keipert, Warren Brown and I drove to Springfield and met with Linda Renee’ Baker, Secretary of the Illinois Department Of Human Services, her assistant Melissa Wright and State Senator Christine Radogno. A big

THANK YOU to Senator Radogno who came through for us to make this meeting a reality.

We met for exactly one hour. Ms. Baker started the meeting with a very brief statement about the shortcomings of many (other) states' "waiting lists", specifically that the opening can occur at one end of the state while the person with developmental disabilities and their parents might live at the other end of the state. At that point, I commented that our advocacy organization (Advocates United), that has been a leading voice in pushing for a "waiting list", feels that it is imperative that those legally responsible for delivering services to people with developmental disabilities know by name who needs what services as well as the name and age of the current caregiver. Ms. Baker seemed to acknowledge her agreement with this philosophy.

Ms Baker then, with input from Ms. Wright, went on to explain that the State under her direction is working on developing a version of what one could call a "waiting list" - they call it the "Developmentally Disabled Needs Inventory".

This "inventory" according to Ms. Baker, would accumulate names of people needing services by geographical location in Illinois to coincide with the 8 network service areas the Department currently has in place. She stated that it would thereafter be the State's goal to focus on approving and encouraging service providers in areas of Illinois where the need was most obvious. She seemed to be relating to us that the "Illinois Plan" is to develop services near to where the person with developmental disabilities currently lives with their parent and/or guardian.

Our committee was taken back and pleasantly surprised by this information about their plan. I mentioned that this was a real departure from what I had heard her predecessor state when he appeared before House and Senate Committees—namely that the State of Illinois would not be served well by a "waiting list" in that such a list would (a) likely result in a lawsuit since he couldn't rely on the Legislature to provide adequate funding and (b) developing such a list would be costly. Ms. Baker stated that the State of Illinois and the Department she heads has had a change of philosophy regarding this matter. We'll see.

The other members and I will discuss more of what we heard at our December meeting. CHANGES ARE COMING! HAPPY NEW YEAR TO ALL.

Back to top

NEWS BUT not on the front page

GOVERNOR RYAN CUTS DISABILITY PROGRAMS

While refusing to cut an appropriation of \$6 million for continued refurbishment of the State Capitol Building, including such necessities as historically correct carpeting and refurbished crystal chandeliers, Governor Ryan has not shrunk from yielding the budget ax to programs serving persons with developmental disabilities in his efforts to cover a projected \$500 million shortfall in State revenues. Even when times were good, DD programs didn't get much but when times get rough, it seems that the poor, elderly, sick and people with disabilities get hammered. Community agencies were to get a paltry 1/2 of 1% Cost Of Living Increase for FY2002. That's gone. Now we hear that the Illinois Center for Rehabilitation & Education (formerly known as the Illinois Childrens' Hospital School) operated by the Office of Rehabilitation Services, DHS, is to be closed. The severely disabled children there will have to go somewhere. Many residents and their families fear nursing home placements. Advocates United opposes this closure.

Meanwhile, at the recent meeting of the Statewide Advisory Committee Meeting, State officials asked the members representing the networks statewide to form groups and come up with some suggestions on what to cut in the budget. Unfortunately, the groups had to work only on the DHS budget rather than the entire State budget with millions for sports teams, land in Peotone, the Illinois Coal Industry, McCormick Place and, yes, historically correct carpeting at the State House.

Back to top

#### KILEY CENTER EVALUATION FINAL REPORT

In the spring of 1995, the Governor announced he was going to close the Kiley Developmental Center in Waukegan, Illinois within two years and move its approximately 400 residents to the community and/or other State facilities. The Institute on Disability & Human Development, University of Illinois and the Illinois Council On Developmental Disabilities teamed up to study how the residents would fare as a result. Because of a "firestorm of protest," the closure did not take place so the evaluation was scaled back to study how people who did move to the community did as compared to similar people who stayed on. In the conclusion of their report, project coordinators Glen Fijiura, Nancy Fitzsimons-Cova and Christina Bruhn make the following observation which sheds some much needed light on the current battle between those who support larger facilities and those who insist only on small community alternatives. They write:

"The (original) charge in this evaluation was to assess the impact of closure on residents moved from Kiley. In the end, it was an evaluation of a limited number of transfers. Among these transfers, the analysis suggest the "impact" - defined in terms of health, behavior, inclusion, satisfaction, and supports- was modest. Neither cataclysm nor miracle occurred.

We are not surprised by the lack of great or substantive differences. This was not a comparison between paragons of opposing services' philosophies but rather of two systems attempting to do their best with limited resources under often trying circumstances. Kiley was not an institutional warehouse. The community programs were

not always exemplars of integration, inclusion and choice. Throughout our evaluation, we encountered staff of great talent and devotion in both institutional and community-based programs... There is a great temptation to frame the data in terms of the simple question—"which is better?" But such comparisons are a misdirection. Where our fellow citizens with intellectual disabilities should live is fundamentally a question of values. What we should value is not an empirical issue. Our bias is that all should be served in the community but acknowledge that the community must do much better. As the data show here, living beyond the walls of the large congregate setting is not an outcome in itself. It is merely the beginning of a process. Otherwise lives remain limited and choices still constrained. This the data makes very clear."

This observation seems to contradict the assertion made in Federal Court by State officials that "All ICFsDD are institutions no matter the size, and all CILAs are not." While size is undoubtedly a factor, the University of Illinois data does not seem to support that generalization.

Back to top

## A NEEDS INVENTORY ISN'T A WAITING LIST

The Statewide Advisory Council's Committee on Service Gaps has expended Herculean efforts putting together a survey of unmet needs for service providers and individuals. If the survey developed is approved by the DHS lawyers, it will be sent out to hundreds of providers and thousands of consumers. The goal is to identify "service gaps". State officials are trying to give the impression that this is the answer to the lack of a State waiting list of people waiting for services. IT IS NOT. The Medicaid statute does not mandate services to gaps but to real individuals. The proposed needs assessment for individuals deliberately omits anyone's name or address thus not obligating the State to do anything. That's why the State lawyers have to approve it: to make sure the State isn't obligated to serve anyone. WE STILL NEED A WAITING LIST BILL. State Representative Renee' Kosel (R-38) and State Senator Christine Radogno (R-24) have agreed to sponsor it this session. Advocates United members urge everyone to support it. Stay tuned.