

# PARENTS ASSOCIATION, INC. SLSSH BELLEFONTAINE HABILITATION CENTER

10695 BELLEFONTAINE ROAD  
ST. LOUIS, MO 63137

PHONE 314-340-6002

WEBSITE [www.ParentsAssociationBHC.com](http://www.ParentsAssociationBHC.com)

## NEWSLETTER

MAY 2012

PARENTS ASSOCIATION MEETING

**SUNDAY, MAY 6, 2012 2:00 p.m.**

GYM IN THE MULTIPURPOSE BUILDING, BHC



All Parent Association members, friends and staff are invited. Keep up with the latest news about Bellefontaine Habilitation Center. Bring your talents and expertise for our advocacy efforts. With everyone's involvement, the lives of the residents at BHC will be the best possible. All are encouraged to stay informed and take some action. Attend a parents meeting, talk with other families, share your concerns and ideas, write a letter, email a message, or make a phone call to help provide a safe, healthy, and supportive environment for the residents of BHC and others. They have no voice but ours, so we must continually speak up for them. Refreshments served.

### 2012 PARENT ASSOCIATION MEETING DATES – Mark your calendars

MAY 6

AUGUST 12

NOVEMBER 11

**The 2012 legislative session ends May 18, 2012. Senate Bill 449 introduced by Senator Scott Rupp and House Bill 1077 introduced by Representative Zach Wyatt** would have closed habilitation centers in the next few years, and was a threat to our legal guardianship. At this time it appears neither bill will pass. Ongoing education about the needs of our family members is always a must. Keep in touch with your state and federal legislators.

**Allowing new long-term admissions to habilitation centers** is supported by families across the entire nation. see pp 4-6

**The federal Title 19 survey team was on campus 3/05-3/15.** No deficiencies were noted in the areas of active treatment, client protections, and staffing. The survey team was very complimentary of staff and their interactions with the individuals. These annual federal surveys of habilitation centers must meet **8 conditions of participation: (CoPs):** Management; Client Protections; Facility Staffing; Active Treatment; Client Behavior and Facility Practices; Health Care Services; Physical Environment; and Dietetic Services. The eight CoPs comprise **378 specific standards and elements.** Serious deficiencies must be corrected within 90 days; other deficiencies must be corrected within a year. Failure to correct deficiencies results in loss of certification and loss of Medicaid funding.

**Waiver funding** for community placements actually waive some of the federal standards to which habilitation centers are held.

**The new homes** are waiting to be reviewed by federal inspectors of Department of Health and Human Services. Some renovations in other existing homes have been completed.

**State budgeting for maintenance and improvement of habilitation centers** is an ongoing necessity to provide a safe, healthy, supportive environment for residents.

**The safety, health, and well-being of the high needs persons** now living in habilitation centers are at risk because of the no new admissions policy, closing of habilitation centers, and legislators proposing closures.

**Waitlist for services of as 4-1-2012:** 233 residential 4,341 in home 4,574 TOTAL

**What action will you take** to ensure habilitation centers remain open?

**Keep informed. Take action. Together we can make a difference.**

Mary A. Vitale, President, Bellefontaine Parents Association

**TRIBUTE FUND**

Celebrate a birthday or anniversary, offer get well wishes or congratulations, remember a loved one by sending in a tribute - support the residents at Bellefontaine Habilitation Center. A few examples of the use of funds are: annual picnic, Christmas gifts and decorations, birthday cakes and presents, holiday decorations, treats and dances, household items, and special programs. The tribute form is on the last page of the newsletter.

<u>DONOR</u>	<u>RECIPIENT</u>	<u>OCCASION</u>
Natale Lucido		donation



**IN MEMORIAM:**

JIM MULVANEY....ONE OF OUR VERY BEST FRIENDS....IS GONE.

“Mulvaney was a long-time member of the Bellefontaine Habilitation Center Parents Association. For many years he was responsible for a great number of improvements in the field of developmental disabilities. He always kept a close eye on what was happening at Bellefontaine. He was always there for those who were unable to speak in their own behalf. Mulvaney’s absence will be heavily felt. Our hearts are with the Mulvaney family in their loss.



**FUNDS APPROVED BY PARENTS ASSOCIATION BOARD**

- \$ 300 Valentine Candy
- \$ 300 Easter Candy



**\$31,643** was the total funds raised by the Hidden Treasure Thrift Shop for 2011. All funds are used for the benefit of BHC residents. The volunteers at the BHC Hidden Thrift Shop deserve a **huge thanks of appreciation** for their dedicated work. Shop at the Hidden Treasure Thrift Shop and find some spring/summer bargains.

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**Thanks** to the following for their donations to benefit the residents at Bellefontaine Habilitation Center: Knights of Columbus Fr. Griffin Council #3586 Tootsie Roll Drive.

**RAM DUES FOR 2012**

The Mental Retardation Association of Missouri (RAM) requests your support for RAM’s efforts on behalf of all state habilitation centers in Missouri. Annual dues are \$5.00. Please make checks payable to RAM and mail to: Norma Lingle  
1010 DuBerry Lane  
St. Louis, MO 63138

**PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2012**

Dues are \$5.00 a year. Make checks payable to Parents Association, Inc.

Mail to: JOHN AHLQUIST  
7711 Bonhomme  
Ste 850  
Clayton Mo 63105



**RAM LETTER TO GOVERNOR JAY NIXON (excerpts)**

In a letter to Governor Jay Nixon, dated February 27, 2012, president Betty Coll states that:

“RAM is an organization of families who have residents in Missouri’s state habilitation centers. These centers do an excellent job of serving those who have severe and profound intellectual disabilities. The services for their range of mental retardation would be far more costly and difficult to provide in scattered community provider homes.

Families are being told that habilitation centers are not available.

Our concern is that the Department of Mental Health policy of freezing admittance to habilitation centers is not only depriving but threatening the lives of those who have the most serious disabilities.

RAM is requesting that the Department of Mental Health’s freeze tactics and bias against state habilitation centers be discontinued. These centers generate millions of federal dollars each year that could be used to maintain the habilitation centers’ premises.”

The response from the governor was encouraging, stating that this information would be used in future decisions about the care of Missouri citizens diagnosed with an intellectual disability.

The governor has stated previously that **he will not support closing the habilitation centers. “Wiping that out completely is, I think, very dangerous for folks who need that 24-hour care.”(KANSAS CITY nbcactionnews.com posted 02/15/11)**

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**PARENT ASSOCIATION, INC. LETTER TO DR. KEITH SHAFER, DIRECTOR OF MENTAL HEALTH**

18 February 2012

Keith Schafer, Ed.D., Director  
Department of Mental Health  
1706 E. Elm Street  
Jefferson City, MO 65102

Dear Dr. Schafer:

The Bellefontaine Parents Association’s letter dated 11-23-2011 expressed our opposition to the Department of Mental Health policy of no new long term admissions to Missouri habilitation centers.

Your response dated 12-08-2012 states: “However, the Division is not required to use the state habilitation centers to provide ICF/MR services. The Division can purchase ICF/MR services through private ICF/MR providers to meet the individual’s needs and satisfy the family’s decision.”

The private ICF/MR providers on the list given to the Parents Association have been investigated by one of our members. The findings are extremely troubling. Pictures are enclosed.

Three of the six addresses were four family apartment buildings that had no exterior devices to assist any developmentally disabled resident. One facility did appear to be appropriate from the exterior. These four locations are in neighborhoods that are located in and around high crime areas, collapsing buildings, and abandoned properties. These are not safe neighborhoods for severely disabled persons.

The Missouri Department of Mental Health does not satisfy current laws by offering these unsafe private ICF/MR facilities.

**The United States Code states:** (3) individuals with developmental disabilities and their families are the primary decision makers regarding the services and supports such individuals and their families receive **including regarding choosing where the individuals live from available options.**

**The June 1999 Supreme Court Olmstead decision states:** “This Court emphasizes that **nothing in the ADA or its implementing regulations condones termination of institutional settings** for persons unable to handle or benefit from community settings. **Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it.”**

State run habilitation centers are an “available option”, so should be offered as a choice as stated in the U.S. code. Denying choice of state run habilitation centers condones termination of institutional settings, in violation of the Olmstead decision.

The Parents Association expects the Missouri Department of Mental Health to abide by these laws, and allow new long term admissions to Missouri habilitation centers. We look forward to your response in the near future.

Respectfully, Mary A. Vitale President, Parents Association-Bellefontaine Habilitation Center

**NO LETTER REPLY FROM DEPARTMENT OF MENTAL HEALTH**

**There has been no letter response** to the Parents Association letter dated 18 February, 2012 concerning fulfilling the law by offering private habilitation centers as an alternative choice to state run habilitation centers.

To express your opinion about: 1) opposition to the Department of Mental Health's freeze on long term admissions to habilitation centers and 2) concern about offering the extremely inadequate private habilitation centers to fulfill the **CHOICE** mandate in current law, CONTACT:

**DEPARTMENT OF MENTAL HEALTH**

Keith Schafer, Director of Department of Mental Health  
Bernard Simons, Director-Division of Developmental Disabilities  
April Maxwell, Director-State Operated Services  
Jeff Grosvenor, Administrative Services



Department of Mental Health  
1706 E. Elm Street  
Jefferson City, MO 65102  
573-751-4122  
1-800-364-9687  
[www.dmh.mo.gov](http://www.dmh.mo.gov)



**GOVERNOR JAY NIXON**

P.O. Box 720  
Jefferson City, MO 65102  
Phone: (573) 751-3222      [www.mo.gov](http://www.mo.gov)

**Your MISSOURI STATE SENATOR AND REPRESENTATIVE**

Missouri Capitol Switchboard: 1-573-751-2000  
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**FAMILIES ACROSS THE NATION SUPPORT HABILITATION CENTERS (excerpts)**

**MISSOURI:** Please vote to keep habilitation centers, such as Bellefontaine Habilitation Center, open and admitting new long-term residents. BHC is my son's home. He, and many like him, are unable to function in a community setting. We need to keep the Hab centers for the well-being of the community and the hab center residents. These centers provide a structured, comprehensive, cost-effective, & stable home for the most severe degrees of mental retardation and physical disability.  
Jeanette Craig      February 12, 2012      email to legislators

**MISSOURI:** We are sending this e-mail in support of keeping habilitation centers open and allowing new long-term admissions to these centers. They provide comprehensive and very cost effective care to Missouri citizens with the severest degree of mental retardation and the highest degree of physical and behavior impairments.  
Robert J and Georgia F. Powers      February 25, 2012      email to legislators.

**MISSOURI:** We know what is best for our son because we can see it on his face and in his eyes every time we see him. He is a man finally comfortable in his skin. Can you imagine what a relief that is for him after all of these years? This is what the Habilitation Centers accomplish for all of our severely challenged adults in the state of Missouri through their hard work, patience and dedication. We should be celebrating them instead of threatening their livelihood. Closing the centers would be a disaster that future generations would have to correct.      Theresa Barnes      March 18, 2012      email to legislators

**MISSOURI:** The state centers work! They are not "relics of the past" or some formidable "walled institution", they are homes. A home that is needed by many who do not have the skills to cope in a less structured or protected environment.  
Darrell Barnes      March 17, 2012      email to legislators



**FAMILIES ACROSS THE NATION SUPPORT HABILITATION CENTERS (excerpts) cont.**

**MISSOURI:** The residents of the habilitation centers enjoy communities that afford acceptance in familiar environments with on-site necessary services, as originally promised, as well as opportunities to develop and maintain their level of innate abilities. It is obvious that the habilitation centers need to not only be kept open, but they should be expanded to meet the needs of those on the lengthy waiting lists desperate for lifetime homes. Where are the voices of the people who are willing to speak up for the most vulnerable?  
Jean A. Ambrow February 10, 2011 St. Louis Post Dispatch

**ILLINOIS:** I speak as the president of the Illinois Nurses Association, which represents the nurses who work for the Chicago Department of Public Health and at the threatened mental health and developmental disabilities facilities, such as Warren G. Murray Center and Fox Developmental Center. And I speak even more strongly as the mother of a Murray Center resident. I understand the risks of moving the disabled to lesser, inadequate levels of care and I am frightened for those residents threatened by these closures. What will happen when these private providers of mental health and developmental disabilities services go unpaid by the state of Illinois? Where will those now provided services through public health clinics and state operated mental health and developmental disabilities centers go when the private providers close their doors for lack of payment?  
Karen Kelly March 30, 2012 Belleville News-Democrat

**ILLINOIS:** (about closing center in Jacksonville, IL): "He cannot live in a community setting," "He tried to do it twice. He has literally physically destroyed two group homes. He is not a candidate for the community."  
Dr. David Iacono-Harris February 27, 2012 The State Journal-Register

**ILLINOIS:** Parents of the developmentally disabled persons living at the center (Jacksonville) say their children need the stability of a state institution. Many have tales of previous community and group home arrangements that ended in suffering and abuse.  
March 9, 2012 WUIS News

**FLORIDA:** The Developmental Disabilities Assistance and Bill of Rights Act considers the issues of "self-determination, independence, productivity, and integration and inclusion in all facets of community life" for individuals with developmental disabilities. And also states that families are the primary decision makers under Federal Medicaid Rules –Too often those with profound disabilities are put into the same category as those who can function in a general community setting. But for those who need constant licensed care, the community is not prepared to serve this population, so for those like my grandson, a Developmental Center is the only life he will ever know—though he does not know where he is. Our grand daughter is happily living in a group home as her condition warrants such placement and as our choice— Families are the Primary Decision Makers. Virginia L. C. RN BSN PHN CDDN April 3, 2012 Disability Blog

**FLORIDA:** The Department of Justice has lost sight of individuals. In one broad stroke it will wipe out a meaningful residential option for our most challenged citizens with intellectual disabilities, with no reasonable solutions. The "community" alternative does not address the serious limitations of our more dependent people. The fundamental issue of safety cannot be resolved by a "community" which often makes them victims of molestation, neglect and abuse. States are required by Federal law to offer individuals who are eligible for Medicaid Home and Community Based Waiver services the choice between community-based care under the waiver program or institutional services. We respectfully urge you to take action to remedy this deplorable situation. Lila Klausman, Pres. Parents Planning Programs (PPP)

**UTAH:** Talk all you want to about "awareness" and "civil rights," but by not allowing placement in what you consider an "institution" for my son you are denying his civil rights. There is a minority of people with disabilities who need a controlled and safe environment and my son has that in a campus setting at a congregate care facility. Yes, we have tried many other alternatives and he has suffered serious injuries. Just read the definition of "self-determination" in the dictionary and you will see that it is a subjective determination for someone who is non-verbal and not culpable. There is not a "one size fits all" situation.  
Mary P April 3, 2012 Disability Blog

**VIRGINIA:** The Northern Virginia Training Center is also a 'Regional Community Support Center,' which means specialized medical and dental care is offered to the state's entire disabled population, and graduate-level staffers receive training for developmental disability medicine and dentistry, among other fields. Anthony says NVTC provides a valuable and irreplaceable service to many families who, like hers, constitute "a small minority of a minority." But don't get rid of something, the part that's working in Virginia.  
Jane Anthony December 20, 2011 Coastline Pilot Fairfax County  
This is their community... this is as much freedom as they can handle...they are living life to the fullest.  
Jane Anthony March 15, 2012 WUSA9 News



**FAMILIES ACROSS THE NATION SUPPORT HABILITATION CENTERS (excerpts cont.)**

**GEORGIA:** That (community placement) could prove difficult to comply with in the case of Gracewood patients such as Erica Knighton, who doesn't speak, suffers from seizures and has the functional capacity of "an infant," said her mother, Ann, the president of the East Central Georgia Family Council. Yet the family has been told that Erica pointed to a picture of a house and said she wanted to go there, a story her mother finds ridiculous, and a staff member put a pen in Erica's hand and helped her sign some papers. "They're (trying) to railroad people out," Knighton said.  
Ann Knighton      January 18, 2011      Augusta Chronicle

**ARKANSAS:** The attorneys from the Department of Justice (DOJ) do not respect the decisions of the guardians of their loved ones to allow the individual to reside where they choose. During these lawsuits and settlements, the DOJ assumes that all individuals should be removed from their homes and be required to hire their own staff and find housing, physical therapy, dentists, doctors, psychologists, care-givers, transportation, occupational therapy, etc. There is no way in the world our daughter Kim could hire her own staff and manage her own care/needs at her mental age.  
Alan Fortney testimony U.S. House of Representatives Committee on Appropriations/Subcommittee on Commerce, Justice, Science & Related Agencies      March 22, 2012

**ARKANSAS:** The Civil Rights Division's programs called "Enforcement of the Integration Mandate of the Americans with Disabilities Act (ADA) and Olmstead v. L.C." are aggressive legal actions against states which operate licensed, Medicaid-certified congregate care programs for individuals who have been adjudicated incompetent and whose continuous care is beyond their families' capacities. The Division's mission is to eliminate the option of state-operated congregate care for individuals with disabilities in the misguided notion that the Division knows what is best for my son and other individuals with severe and profound disabilities rather than their legal guardians who have made the residential decisions for their family members. The Division's actions have caused and continue to cause enormous stress and anxiety for the families and guardians.

Federal tax dollars should not be spent in undermining and dismantling a system of care that is absolutely essential to many persons with disabilities. What is often overlooked, particularly by those in authority who are far away from the daily responsibilities of care and who are not responsible for providing the close care required, is that the population with disabilities involved in the Civil Rights Division's legal actions are extremely difficult to care for and to support, wherever they may live. It is our position (including those like my family who are parents and families of the critically disabled individuals at risk) that congregate care facilities, adequately funded, offer the most suitable settings and programs for a particular group of those suffering from some of the most severe forms of cognitive -developmental disabilities,

Justice Kennedy, joined by Justice Breyer, wrote in his concurring opinion, joining the majority of four: **"it would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care into settings with too little assistance and supervision. 527 U.S. 610. Justice Kennedy's prognostic fear is a present day reality. Conclusion:** It is not in the public interest for a federally funded entity through power of its office and out of the public view to coerce a state to cease operating programs which have historically proven successful in assuring the health and safety of persons with lifelong, severe cognitive disabilities. It is deeply offensive to me, my family and many others that our federal government through the U.S. Department of Justice is empowered to intimidate state authorities into unfair settlement agreements resulting in closures of our children's safe homes. **Request :** The comprehensive and devastating reach of the Civil Rights Division agenda on the most vulnerable among us requires active, vigilant Congressional oversight.  
Carole Sherman testimony U.S. House of Representatives Committee on Appropriations/Subcommittee on Commerce, Justice, Science & Related Agencies      March 22, 2012

**WISCONSIN:** Commissioner Lewis is either unable or unwilling to accept my son, and others similarly situated, as individuals with ID/DD that have far more intensive needs than others and ARE BEST served in a highly specialized institution. As the head of a federal agency that receives public funds to advocate for ALL individuals with ID/DD, there is no place for personal biases from Commissioner Lewis.  
Becca      April 3, 2012      Disability Blog

**IOWA:** Finken is a long-time disability advocate in Iowa and nationally. Locally she is a staunch supporter of Glenwood Resource Center, a licensed residential program for people with profound intellectual disabilities, where her son, Seth, is a resident. "At Glenwood, Seth can be all he can be," remarked Finken. "He's so well-cared for and happy. As parents, his happiness, good care and comfort are all we can ask for."...one size does not fit all," said Finken. Glenwood Resource Center is federally-certified to care for people with complex needs.  
Sybil Finken      November 10, 2011      OpinionTribune

**FAILURE OF PAST POLICIES-WHY USE THEM AGAIN?**

The book, Madness in the Streets: How Psychiatry and the Law Abandoned the Mentally Ill, by Rael Jean Isaac and Virginia C. Armat, details how in the 1970's and 1980's, academic, medical, social, legal, and political fields joined their "best practices" to develop a national policy concerning persons with mental illness based upon a **false idea** --that all persons with a mental illness could "live in the community" no matter what their disabilities. That national policy had disastrous results of neglect, abuse, and death of the mentally ill.

Currently, the national policy concerning persons with intellectual and developmental disabilities is going down the same road with the same **false idea** that state operated facilities are no longer needed, and that living "in the community" should be the only option of care. This "best practices" policy is being supported by many in academic, legal, and political fields against the better wishes of legal guardians.

**From Book: Madness in the Streets:**

**From family experiences:**

CARE OF PERSONS WITH MENTAL ILLNESS	CARE OF PERSONS WITH MENTAL RETARDATION
1940-1960 Good reasons for major reform for more humane treatment	1940-1960 Good reasons for major reform for more humane treatment
1960s <b>The false idea</b> developed in the academic field that mental illness was not an abnormality-just a different level of reality. If the label of mental illness was taken away, somehow the condition improves. This greatly affected the direction of treatment in our national policies.	1980s - present <b>The false idea</b> developed that community placement should be the only option for persons with mental retardation. Community placement is promoted as better but cheaper. The Institute for Human Development, UMKC backs this <b>false idea</b> . Much of our national policy is now based on this <b>false idea</b> .
1960s-1980s Mental health professionals begin to accept this <b>false idea</b> .	1980s - present Mental health professionals use this <b>false idea</b> to advocate for closure of state run "congregate care". Here in Missouri, the vision is to not use habilitation centers as long term residential campuses, but only as short term crisis centers as needed by community providers.
1960s-1980s Major organizations such as National Mental Health Association and National Institute of Mental Health accept this <b>false idea</b> .	1990s - present Missouri Planning Council and ARC-US are just two agencies using this <b>false idea</b> to promote closing all habilitation centers.
1960s - 1980s The legal field (ACLU and Protection & Advocacy agencies) begins to use this <b>false idea</b> to sue for rights of mentally ill, especially to refuse treatment and to question need for guardianship.	1980s - present The legal field, especially the Dept. of Justice, uses this <b>false idea</b> to file suits against states to close many facilities across the nation.
1960s -1980s Politicians accepted this <b>false idea</b> because they saw a way to save money and expand civil rights. The promise of saving money by doing good was irresistible.	1980s - present Politicians have backed this <b>false idea</b> of community being cheaper and better. Again, the promise of saving money by doing good is very alluring.
1960s - 1980s A national policy developed to encourage mass deinstitutionalization of persons with mental illness. Anything in the community was better than an institution.	Present - A national program, The Freedom Initiative signed by President Bush in 2001, has granted millions of dollars to states to hasten the transfers out of state operated facilities.
1960s - 1980s Reality was that ill prepared community placements, poor supervision, and lack of oversight resulted in abuse, neglect, and death. 1982 statistics from the National Institute of Mental Health states that of the people living in St. Louis shelters or on the street, 56% were the mentally ill.	1980s - present Community placements can be successful. However, national and state reports are revealing such poor supervision that in 2003 Senator Grassley stated that these community placements "should be put on hold...right now there is no accountability." Audits by Claire McCaskill revealed the same poor accountability for Missouri community placements in 2001 and 2005.
1979 <b>Parents formed the National Alliance for the Mentally Ill (NAMI)</b> to educate about the traumatic results policies were having upon the mentally ill and their families. Policies began to be reviewed. Some positive changes began to occur.	1983 <b>Voice of the Retarded (VOR)</b> is formed by parents to advocate on a state and national level for a full continuum of care for persons with mental retardation, including habilitation centers to ensure availability of appropriate services.
Present We are still seeing the disastrous results of the policies today of a <b>false idea</b> .	Present This <b>false idea</b> has increased inappropriate placements in ill prepared community settings resulting in neglect and abuse.

**As Senator Timothy Green of Missouri's 13<sup>th</sup> district has stated during his compassionate political leadership:**

**"When you close a center, you may be closing a life."**

TRIBUTE FUND FORM (please print)

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MAIL TO: ROSEANNE DICKEY #6 HOBBS MILL ST. CHARLES, MO 63303

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PARENTS ASSOCIATION, INC. SLSSH  
BELLEFONTAINE HABILITATION CENTER  
10695 BELLEFONTAINE ROAD  
ST. LOUIS MO 63137

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