

**PARENTS ASSOCIATION  
BELLEFONTAINE HABILITATION CENTER**

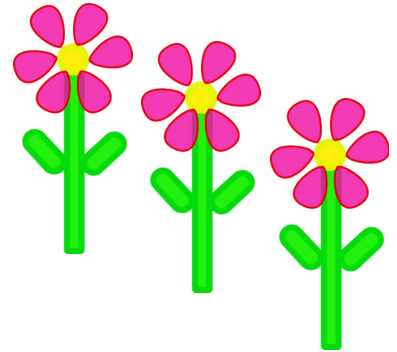
10695 BELLEFONTAINE ROAD  
ST. LOUIS, MO 63137

PHONE 314-340-6002

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

**NEWSLETTER**

**MAY 2015**



PARENTS ASSOCIATION MEETING

**SUNDAY, MAY 17, 2015 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.

**2015 PARENT ASSOCIATION MEETING DATES – Mark your calendars**

MAY 17

AUGUST 9

NOVEMBER 8

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The Parent Newsletter is online at [www.parentsassociationbhc.com](http://www.parentsassociationbhc.com). Pass it along to friends, family, and political leaders.

The switchboard number for Bellefontaine Habilitation Center is **314-264-9100** or **314-264-9101**.

**HAPPY 50<sup>TH</sup> ANNIVERSARY OF PARENTS ASSOCIATION!!** 50 years of dedication and persistence has helped provide the necessary services and a wealth of extra opportunities for residents of Bellefontaine Habilitation Center. The strong influence of the Parents Association has helped to make the Bellefontaine Habilitation Center a safe, healthy and supportive home for the residents.

**Demolition** of the Dietary Building has been completed.

**Renovations** are scheduled for the group homes that have not yet been updated.

**Road repair** is a major need at this time.

**Federal Surveyors will be on campus sometime in the next few months.** These surveys verify that strict federal guidelines are being followed to ensure continued federal Medicaid reimbursements. These strict guidelines also help ensure the safety, health, and well-being of BHC residents.

**Why aren't families given the choice of habilitation center** as mandated by state and federal law? Habilitation center homes are successful, stable, sustainable, comprehensive, consistent and cost-effective.

**Do you know of a family** that might need the services of a habilitation center? Call the Parents Association at 314-340-6002.

**Senate Bill 174 would establish the Missouri Achieving a Better Life Experience (ABLE).** Each state must put regulations in place to participate in the new federal ABLE law that will allow a person who acquired a disability before the age of 26 to open special accounts to save up to \$100,000 without risking eligibility for Social Security and other government programs. Funds accrued in the accounts can be used to pay for education, health care, transportation, housing and other expenses. **Senate Bill 322** would increase the asset limit for an individual receiving Medicaid from \$1,000 to \$5,000 over time (or \$2,000 to \$10,000 for a couple). Final vote before or by legislative session end on May 15, 2015.

**Also, it is always important to watch how the habilitation centers are budgeted,** and how the federal Medicaid reimbursement dollars are spent. [www.mo.gov](http://www.mo.gov) **Keep informed. Take action.** Mary A. Vitale, President, Bellefontaine Parents Association

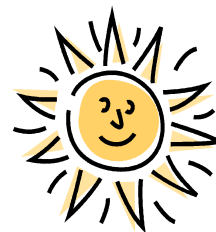
**TRIBUTE FUND**

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 & Rose Mary Lucido Carla Hart		in memory of Earl & Angela Radley donation

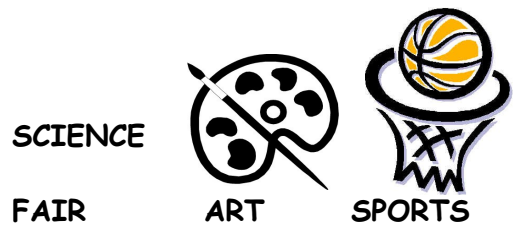
**FUNDS APPROVED BY PARENTS ASSOCIATION BOARD**

\$ 300 Valentine treats, activities  
\$ 300 Easter treats, activities



**Thanks to** the Knights of Columbus for a generous donation to BHC from the proceeds of the annual Tootsie Roll Drive.

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**RESIDENT ACTIVITIES – SO MUCH TO ENJOY**

Recent activities have given BHC residents opportunities and fun. The activities showcase the arts, athletics, education, and fun available on a daily basis on the BHC campus.

Some of the activities include:

**Art projects** were completed by some of the residents and sent to Jefferson City to the Director's Creativity Showcase.

**Special Olympics Basketball** team participated in a tournament in St. Peters and Cape Girardeau.

**Special Olympics Track & Field** events held in April.

**Valentine's Dance** had cupcakes, jello, pudding, cookies and punch. Pictures were taken in front of a giant heart. Everyone received a bag of candy personalized to their dietary level.

**Easter Dance** had cupcakes, jello, pudding, cookies and punch. Everyone received a bag of candy personalized to their dietary level.

**Science Fair Projects** are being started by residents with experiments and displays.

**Thanks to BHC employees** for planning such a wide range of activities for BHC residents, and to the Parents Association for funding of some of the activities.

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The Parents Association supports keeping habilitation centers open and allowing new long-term admissions to these centers. These centers provide comprehensive, **very cost effective care** to Missouri citizens with the severest degree of intellectual disability and the highest degree of medical, physical, and behavioral impairments.



## **HAPPY 50<sup>TH</sup> ANNIVERSARY TO THE BELLEFONTAINE HABILITATION CENTER PARENTS ASSOCIATION!!**

The amazing accomplishments of the Bellefontaine Habilitation Center Parents Association (first named Parents Association of the State School and Hospital) are the results of persistent dedication and hard work.

For 50 years the Parents Association has been vigilant in seeing that the intellectually disabled residents of the Bellefontaine Habilitation Center (BHC) receive necessary services for their safety, health, and well-being. The organization has been continually active on the local, state and national level to give a voice to the residents who have no voice of their own. Over the years, major funding has been earned from the untiring work of the volunteers of the Hidden Treasure Thrift Shop. These funds, along with donations and tributes from members and others, have been used to benefit the residents. Each year thousands of dollars from the Parents Association have provided an abundance of enjoyable extras for the residents. Also, to express appreciation to employees of BHC, the Parents Association has held the Annual Employee Recognition Dinner.

### **1960's - Parents organized**

It all began in 1965 with a group of 27 dedicated parents who developed plans to organize a Parents Association to work for better services and living conditions for the residents of the then St. Louis State School and Hospital. This organization of parents meant having the power to work for positive change with legislators and the Department of Mental Health administration.

Over the next few years, many other parents, relatives, guardians, and friends joined the Parents Association. They volunteered time, made donations, and began to help form public policy about the care of Missouri residents with an intellectual disability.

### **1970's - Parents Association is a force for positive change**

The 1970's were filled with petitioning for new group homes on the grounds. Letters, phone calls, testifying at hearings of the Missouri legislature in Jefferson City, personal visits with legislators, and discussions with the Department of Mental Health made this dream come true.

In 1974 Governor Christopher Bond attended the groundbreaking for the first 10 new group homes on the campus. More group homes were built in the next several years for a total of 34. Plans for construction of the therapeutic pool also began.

Other positive changes at this time were the establishment of the Birthday Cake and Birthday Gift Fund which provided a birthday cake and gift for every resident. Major purchases such as televisions were paid for by the Parents Association.

### **1980's - Parents Association continues to represent BHC residents**

The multipurpose building was built providing new offices, program areas, and a gymnasium.

The 1980's brought about a concerted effort to move residents into community placements because Medicaid waiver money became available. The idea of "deinstitutionalization" began to take hold. The Parents Association persevered to maintain the positive changes that had been accomplished. Ongoing education of the legislators continued.

Thousands of dollars from the Parents Association continued to provide fun and enjoyment for the residents.

### **1990's - Parents Association continues to educate**

Community placements were on the rise. The Parents Association continued to educate legislators about faulty cost comparisons of community placement and habilitation centers. It was pointed out that habilitation centers costs were all inclusive, whereas costs of community placements did not include everything offered in habilitation centers. Frequent contact with legislators continued.

Funding for extra activities for the residents continued.

### **2000 to present - Parents Association stands firm**

In 2005 Governor Matt Blunt called for the total closure of the Bellefontaine Habilitation Center. Legal representation was sought, numerous trips to the Capitol in Jefferson City were made, editorials were published, questions from news reporters were answered, and a Keep BHC Open rally was organized with the help of Metropolitan Congregations United. Once again, a vocal and persistent Parents Association defended the rights of the residents of Bellefontaine Habilitation Center. With the devoted support of then Representative Gina Walsh (now Senator) and Senator Tim Green (now retired), appropriations were approved to build 4 new buildings, to renovate existing group homes, and to raze older buildings. Jerry Ford and Jim Mulvaney also supported and worked hard for the new buildings and renovations.

The 4 new group homes opened in 2012. Renovations and demolition are almost complete.

To the Parents Association's great dismay, several of the group homes have been torn down.

**HAPPY 50<sup>TH</sup> ANNIVERSARY TO THE BELLEFONTAINE HABILITATION CENTER PARENTS ASSOCIATION!!, CONTINUED**

The Parents Association continues funding for extras such as:



- BIRTHDAY CAKES AND GIFTS
- HOLIDAY PARTIES
- HOLIDAY DECORATIONS
- HOME FURNISHINGS
- SPECIAL PROGRAM FUNDS
- PICNIC FUNDS
- DANCE BANDS
- CAMP FUNDS
- STAFF APPRECIATION



For 50 years many devoted board members, committee members, and general members have given time and talent to the Parents Association to enable the association to be an influential leader concerning policies that affect the daily lives of the BHC residents.

The following quote from VOR, a national nonprofit organization advocating for high quality care and human rights for all persons with intellectual and developmental disabilities, points to the success of the Parents Association and gives direction to the future efforts of the Parents Association:

“Families are the most effective voice for their disabled loved ones.”

“They know best. It is critical that families be on the frontlines educating legislators and state officials about the unparalleled, comprehensive and highly specialized care their loved ones receive.”

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WHAT ACTION WILL YOU TAKE TO ENSURE HABILITATION CENTERS REMAIN OPEN AND OFFERED AS A CHOICE?

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Do you have a relative, friend, or community leader that would be interested in the Parent Association? 2015 MEMBERSHIP DUES ARE \$5.00 annually. Pass along the membership form.

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**PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2015**

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

NAME \_\_\_\_\_

STREET ADDRESS \_\_\_\_\_

CITY, STATE, ZIP CODE \_\_\_\_\_

EMAIL ADDRESS \_\_\_\_\_

PHONE NUMBER \_\_\_\_\_

NEW MEMBER     yes    no    

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

**If you are a new member, please let us know so that you can receive our newsletter.**



**THE AMERICANS WITH DISABILITIES ACT (ADA) IS 25 YEARS OLD, IS MISUSED**

The Americans with Disabilities Act of 1990 (ADA) has been beneficial to many persons with disabilities. However, it has been misused to mandate the closure of intermediate care facilities for individuals with an intellectual disability (ICFs/IID). These facilities are called habilitation center homes in Missouri.

The Public Insight Network has asked for submissions to the question: What is it like to live with a disability 25 years since the ADA became law? (by Tess Homan and Darby Fitzgerald)

The following responses to the questions were sent in by Mary Vitale to make known how the ADA has been misused:

1. What has changed and what hasn't changed since the ADA was passed?

**Response:** The benefits of the ADA are that there has been an increase in reasonable accommodations in many public places, public transportation and the workplace for more accessibility for those with disabilities. Developing the abilities of persons with disabilities has been successful.

2. Have you experienced discrimination at work or in your day-to-day life because of a disability? If so, please tell us more.

**Response:** I do believe persons like my brother with severe intellectual and physical disabilities are being discriminated against because the ADA is being used to close their facility homes.

3. Do you think the ADA has benefitted people with certain disabilities more than others? If so, how?

**Response:** The ADA has made the lives of persons with severe intellectual and physical disabilities worse because they are being forced from their chosen home of an intermediate care facility for individuals with an intellectual disability (ICF/IID).

The ADA was supposed to be about more choice, not less.

4. What else should we know or cover about this topic

**Response:** The Americans with Disabilities Act of 1990, and the 1999 Supreme Court Olmstead interpretation of the ADA has benefited many persons with disabilities.

Alarming however, the ADA and the Olmstead decision has been misused as a mandate for total deinstitutionalization of persons with intellectual disabilities without regard for individual need and guardian choice.

The Department of Justice has been especially aggressive in closing intermediate care facilities for individuals with an intellectual disability (ICFs/IID) saying that the civil rights of these individuals are being violated just because they live in an ICF.

To avoid costly litigation states comply with these misguided demands of the DOJ. If there is any individual, guardian, or family input it is widely ignored. Closures of ICFs/IID continue, putting the safety, health and well-being of persons with severe intellectual and physical disabilities in harm's way. Nationwide, there are numerous abuse and death reports about residents who were forced from their ICF homes.

The ADA and the Olmstead decision were supposed to bring about more choice, not mandate closure of ICF/IID homes that are successful, comprehensive in services, and cost effective.

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About the Public Insight Network

From the website: "Founded in 2003, American Public Media's Public Insight Network is a platform for connecting trusted journalists with knowledgeable sources and for fostering journalistic excellence, innovation and collaboration."

**TAKE ACTION:**



To submit responses go to:

[www.publicinsightnetwork.org/source/en/insight/10f150262b24/what-is-it-like-to-live-with-a-disability-25-years-since-the-ada-became-law](http://www.publicinsightnetwork.org/source/en/insight/10f150262b24/what-is-it-like-to-live-with-a-disability-25-years-since-the-ada-became-law)

## **SUPPORT FOR OUT-OF-HOME PLACEMENT FOR CHILDREN AND ADOLESCENTS WITH DISABILITIES**

A clinical report was published by the American Academy of Pediatrics concerning out-of-home placement for children and adolescents with disabilities in Pediatrics – the Official Journal of the American Academy of Pediatrics Vol. 134 No. 4 dated 10-1-2014. The authors were Sandra L. Friedman, MD, MPH and Miriam A Kalishman, MD.



The conclusion from this clinical report states:

“Despite the fact that considerable progress has been made to support children with significant developmental and/or medical problems in the home setting, there continues to be a need for other options of care and living arrangements. The decision to have a child live away from the family home is difficult and complex. Although consideration must be given to providing each child with the best resources and support as possible, the family’s needs, stressors, capacity, and relationships must also be considered. The importance of trying to support families to care for the child at home cannot be overstated. However, parents of children with significant special health care needs may, at some point, consider out-of-home placement.”  
(emphasis added)

### **SPECIAL NEEDS PERSONS NEED SPECIALIZED MEDICAL CARE**

A national Autism Treatment Network providing one-stop centers for autism care recognizes that special needs need specialized care not available in general medical care.

The centers that are part of the network offer kids and adolescents with autism consolidated services of pediatricians, psychiatrists, neurologists and gastrointestinal specialists with experience treating those on the spectrum. Also, autism research is conducted by the medical centers.

The Knights of Columbus Child Development Center at SSM Cardinal Glennon Children’s Medical Center in St. Louis is one of these centers.

To find out more about the Knights of Columbus Developmental Center: Phone: 314-577-5609

Website: [www.cardinalglennon.com/MedicalSpecialties/Developmental%20Pediatrics/Pages/default.aspx](http://www.cardinalglennon.com/MedicalSpecialties/Developmental%20Pediatrics/Pages/default.aspx)

### **MORE SPECIALIZED MEDICAL CARE-LEE SPECIALTY CLINIC IN KENTUCKY**

The Lee Specialty Clinic in Louisville, Kentucky opened in June 2014. The clinic provides specialized care for persons with intellectual disabilities. (website: [www.leespecialtyclinic.com](http://www.leespecialtyclinic.com) phone: 502-368-2348)

Following are quotes from an article about the Lee Specialty Clinic, entitled “An Oasis of Care and Caring for People with Intellectual Disabilities” by Dan Barry, in the New York Times dated 12-30-14.

“For years, parents like Ms. Kramer have struggled to find compassionate health care for their adult children with profound disability, among the most medically underserved populations in the country.”

“The deficiencies in health care for people with intellectual disability have been cited by the surgeon general, the American Medical Association and the American Dental Association, among others.”

“The 17,000-square-foot clinic, which opened in June, offers certain amenities. A reception area with natural light and easy-to-clean cushions. Extra-wide halls. Scales designed to weigh people in wheelchairs. An overhead tram to lift patients into dental chairs.”

“Just as important, say the clinic’s co-directors, Dr. Henry Hood and Dr. Matthew Holder, is its staff, trained to understand what their patients and families have been through.”

“In addition to providing training for doctors and dentists, the clinic offers full service to families accustomed to embarking on odysseys in search of health care. It provides behavioral, physical, occupational and speech therapy, as well as medical, dental and psychiatric care, for about 500 patients, though that number is expected to grow. Families can now meet with several specialists at once to develop a health care plan.”

To read the entire article, go to: [www.nytimes.com/2014/12/31/us/in-louisville-an-oasis-of-care-for-the-disabled.html?\\_r=0](http://www.nytimes.com/2014/12/31/us/in-louisville-an-oasis-of-care-for-the-disabled.html?_r=0)

Also click on video on that page "Challenging Patients" - worth watching.

**PARENT ASSOCIATION COMMENT:** The Parents Association has always supported the specialized care available at the Bellefontaine Habilitation Center, and has been aware of the lack of training for general medical professionals in treating persons with severe intellectual and developmental disabilities.

**NEW VOR SURVEY REPORT IS RELEASED APRIL 2015****VOR SURVEY REPORT**

VOR is a national nonprofit organization that advocates for individuals with intellectual and developmental disabilities, including autism.

“GIVING A VOICE TO FAMILIES AND GUARDIANS - A SURVEY OF FAMILIES AND GUARDIANS OF INDIVIDUALS WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES IN VARIOUS RESIDENTIAL SETTINGS” is the title of an important VOR survey released in April 2015.

Family members of persons who reside in intermediate care facilities for individuals with an intellectual disability (ICF/IID) – (habilitation centers in Missouri) are under-represented in surveys that are sometimes used to further the idea of “deinstitutionalization”.

This VOR survey was an opportunity to give a voice to families who have chosen an ICF home (habilitation center in Missouri) for their family member and to help shape public policy. Non-ICF responses were also included.

Some findings of the Survey include:

**Satisfaction:** ICF respondents indicated a high degree of satisfaction with their individuals’ ICF homes, with the vast majority, 88%, rating the service as exceptional and 69% indicating that their individuals would do poorly in non-ICF homes.

In contrast, just 36% of Non-ICF respondents were highly satisfied with their individuals’ living situations. An equal number of Non-ICF respondents felt that their individuals would do poorly in ICF settings as those who thought they would do exceptionally well.

Most respondents for both surveys were informed about alternatives to their individuals’ current placements based on their own evaluations of different settings and, in some cases, the individuals’ prior placements in other settings.

**Community Integration:** 72% of Non-ICF individuals enjoyed an average to high degree of integration. Significantly, a nearly equal percentage, 73%, of the ICF Respondents also indicated that the level of interaction by their ICF individuals with the broader community away from their homes (“integration”) was average to high.

**Access to Services:** When questioned about the adequacy of access to services, including access to medical care, almost all ICF respondents ranked access as high, as compared to the non-ICF group in which access ranged from low to high.

**Staff Competency:** More direct care workers in ICF settings are subject to background checks before being hired, as compared to direct care staff in Non-ICF settings, according to respondents. Staff training requirements were similar in ICF and Non-ICF settings according to respondents.

**Vocational Opportunities:** For both surveys, nearly half of the respondents indicated that their individual is unable to work. One ICF survey respondent indicated that her individual had “very limited work ability which is done on campus with staff assistance.” For both surveys, of those individuals who could work, most worked in sheltered employment.

**Conclusions:** The responses to the ICF survey revealed a sharp contrast between common misperceptions of “institutions” as segregating and isolating environments and the perceptions of family members and guardians of individuals living in these settings. Based on their own experiences, ICF respondents indicated a high level of satisfaction with their individuals’ ICF homes, staff competency, access to services and community integration.

Especially revealing were the personal examples and responses provided by respondents, primarily families, in response to this question: “What would you like our government to know about the current move to de-institutionalize ICF residents in favor of small community-based facilities?”

What mattered most to families of those receiving care in both ICF and Non-ICF settings was that their family members with I/DD received the care they needed and that their right to individual choice was respected. As so aptly stated by one respondent: **“Good public policies should be based on experience, common sense and humanity. There should be deference and respect for the positions of families who have first-hand experience in the care and treatment of persons with life-long disabilities.”**

All responses are available at [www.vor.net/images/WhatDoUWantGovt2Know.pdf](http://www.vor.net/images/WhatDoUWantGovt2Know.pdf)

TRIBUTE FUND FORM (please print)

ENCLOSED CONTRIBUTION \_\_\_\_\_

IN MEMORY OF \_\_\_\_\_

ON THE OCCASION OF \_\_\_\_\_

PLEASE SEND TO (name) \_\_\_\_\_

(address) \_\_\_\_\_

FROM (name) \_\_\_\_\_

(address) \_\_\_\_\_

MAKE CHECKS OR MONEY ORDERS PAYABLE TO "Bellefontaine Habilitation Parents Association"

MAIL TO: BHC PARENTS ASSOCIATION 10695 BELLEFONTAINE ROAD ST LOUIS MO 63137



**THE HIDDEN TREASURE SHOP**  
**SHOP TILL YOU DROP!! BEST THRIFT SHOP PRICES!!**  
**NOW IN BLDG #1901** FIRST BUILDING ON THE LEFT AS YOU ENTER BHC CAMPUS.

Thanks to the generous hearts and hard work of all the volunteers in the Thrift Shop.

**WEDNESDAYS, 9 A.M. TO 3 P.M. AT BHC**

Please leave donated items at the Parents Association shed near the Thrift Shop.

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

FORWARDING AND ADDRESS  
CORRECTION REQUESTED