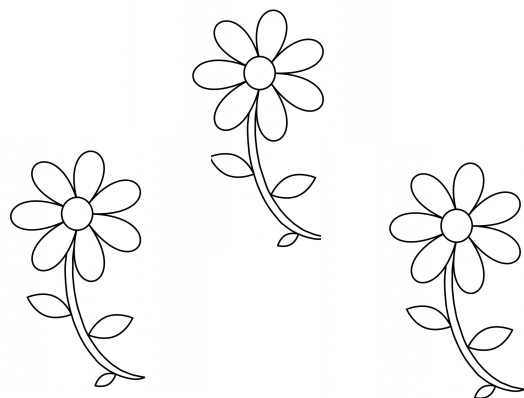


**PARENTS ASSOCIATION  
BELLEFONTAINE HABILITATION CENTER  
10695 BELLEFONTAINE ROAD  
ST. LOUIS, MO 63137**

PHONE 314-264-9100 BHC Switchboard  
PHONE 314-340-6002 Thrift Shop  
WEBSITE [www.parentsassociationbhc.com](http://www.parentsassociationbhc.com)

**NEWSLETTER    MAY 2019**



**PARENTS ASSOCIATION MEETING  
SUNDAY, MAY 19, 2019 2:00 p.m.  
Administration Bldg. Room #10**

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, 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.

**UPCOMING PARENT MEETING: MAY 19, 2019**

**2:00 P.M. IN THE ADMINISTRATION BLDG. ROOM #10**

**2019 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!**

**MAY 19      AUGUST 11      NOVEMBER 10**  
+++++

**Meet with Valerie Huhn, Director of Department of Developmental Disabilities,** and other Department of Mental Health officials at the May 19, 2019 BHC Parent Association meeting. Learn about the latest news. This is an opportunity to have a conversation with Department of Mental Health officials.

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

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

**Federal Surveyors for Title XIX Medicaid funding** were on campus for the annual survey from March 5 - March 12. This comprehensive survey is one aspect of oversight for quality care so that residents live in safe, healthy, supportive homes.

**The survey team was very complimentary of staff,** and of compliance with Active Treatment for the residents. Much appreciation goes to all BHC staff for contributing to a successful survey.

**Road repair** is in the planning stage at this time.

**Education of all legislators is an ongoing necessity** as part of our advocacy for intellectually disabled residents living in habilitation centers. Get to know your legislators. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to [www.mo.gov](http://www.mo.gov).

**The 2019 VOR Annual Conference and Congressional Visits** will be from June 8 – June 12. The conference is a worthwhile opportunity to meet other families and to make visits to U.S. Senate and Representative Offices in Washington, D.C. Think about attending or donating to VOR. Go to [www.vor.net](http://www.vor.net)

**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.

**DONOR**

**RECIPIENT**

**OCCASION**

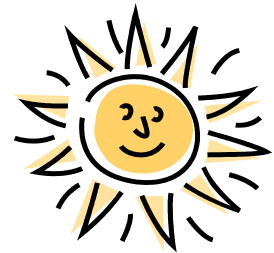
Jeanette Findley  
Lee & Jackie Kearney

donation  
donation



**FUNDS APPROVED BY PARENTS ASSOCIATION BOARD**

- \$ 225.00 Valentine treats for each resident
- \$ 100.00 Valentine decorations for dance
- \$ 225.00 Easter treats for each resident
- \$ 100.00 Easter decorations for dance



THANKS TO THE BIG HEARTS AND HARD WORK OF THE VOLUNTEERS AT THE HIDDEN TREASURE THRIFT SHOP, AND THANKS TO THOSE WHO DONATE FUNDS. ALL PROCEEDS GOES TO BENEFIT BHC RESIDENTS.

\*\*\*\*\*

**BHC RESIDENT ARTISTS AND DIRECTORS CREATIVITY SHOWCASE**



The Director's Creativity Showcase is sponsored by the Missouri Mental Health Foundation, in partnership with the Missouri Department of Mental Health. This annual event displays the artistic talents of people served by the Department of Mental Health.

In 2018, artwork created by a BHC resident titled "Birthday Cake" was chosen to be featured in the 2018 Director's Creativity Showcase Traveling Show.

This year 10 BHC residents, with the assistance of their support staff, entered artwork for consideration and received Certificates of Participation. Their artwork will be displayed at the 2019 Mental Health Champion's Banquet on June 18, 2019.

**WINTER/SPRING RESIDENT ACTIVITIES**



BHC residents have enjoyed a variety of programs and activities on and off campus in the past few months:

**Shopping** - Walmart, Schnuck's, Goodwill, Game Stop, Dirt Cheap, Dollar Tree, Cash America, Family Dollar, 367 Flea Market, Gas Station, Beauty Supply, Dollar General, Five Below, Save-A-Lot, Target, Bath and Body Works, Burlington, Big Lots, MidRivers Mall, QuikTrip, PetsMart, Galleria, Shoe Carnival, Patricia Store, Kohl's, Macy's, Michael's, West Co. Mall, BP Gas Station

**Out to Eat** – McDonald's, Raising Canes, China King, Penn Station, Pappy's BBQ, St. Louis Fish & Chicken, Rice House, Red Lobster, Las Fuentes, Applebee's, Church's, Fazoli's, Dairy Queen, Imo's, White Castles, Culver's, Chili's, Bandana's BBQ, Steak N Shake, Grand Steakhouse, Panda Express, Golden Corral, Subway, Long John Silvers, Chinese Food Place, Hometown Buffet, 54th Street Grill, Fro-Yo's, Sweetie Pies, Waffle House, Hooter's, China House, Incredible Pizza, Best Steak House, Hibachi Grill, Baskin & Robbins, Pizza Hut, St. Louis Bread Co., Ted Drew's, Taco Bell

**Other** - Great Clips, Fox Theater, Barber Shop, Jack of All Fades, SLU Billikens Basketball, ARC Dance, USOC Barber, Delmar Loop, Legends of Hip Hop-Chafeitz Arena, Lewis & Clark Library, Movie, Shriner's Circus, Mills Mall walking, Spanish Lake Park

**On campus activities** – Movies in the gym, Bingo, open gym, Valentines dance, Easter dance

**ANNUAL FEDERAL SURVEY FOR TITLE XIX MEDICAID FUNDING**

The March 2019 federal survey for Title XIX of the federal Medicaid law is an **annual on-site** federal survey of ICFs/IID (habilitation centers) to ensure compliance with 8 Conditions of Participation (CoPs):

1. Management
2. Client Protections
3. Facility Staffing
4. Client Behavior and Facility Practices
5. Health Care Services
6. Physical Environment
7. Dietetic Services
8. Active Treatment

According to the Center for Medicaid and Medicare Services State Operations Manual, Appendix J – “Guidance to Surveyors: Intermediate Care Facilities for Individuals with Intellectual Disabilities”, the 8 CoPs comprise 489 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.

The criteria can be found at:

[www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap\\_j\\_intermcare.pdf](http://www.cms.gov/Regulations-and-Guidance/Guidance/Manuals/downloads/som107ap_j_intermcare.pdf)

**WHAT IS ACTIVE TREATMENT FOR PERSONS WITH INTELLECTUAL DISABILITIES?**

[https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR\\_Glossary.pdf](https://www.cms.gov/Medicare/Provider-Enrollment-and-Certification/CertificationandCompliance/Downloads/ICFMR_Glossary.pdf)



According to the Code of Federal Regulations:

Active Treatment (42 CFR 483.440(a)) Refers to aggressive, consistent implementation of a program of specialized and generic training, treatment and health services.

**Components of Active Treatment:**

**A. Comprehensive Functional Assessment**  
(42 CFR 483.440(c)(3)).

The individual's interdisciplinary team must produce accurate, comprehensive functional assessment data, within 30 days after admission, that identify all of the individual's: • Specific developmental strengths, including individual preferences; • Specific functional and adaptive social skills the individual needs to acquire; • Presenting disabilities and when possible their causes; and • Need for services without regard to their availability.

**B. Individual Program Plan (IPP)**

(42 CFR 483.440(c)). The interdisciplinary team must prepare an IPP which includes opportunities for individual choice and self-management and identifies: the discrete, measurable, criteria based objectives the individual is to achieve; and the specific individualized program of specialized and generic strategies, supports and techniques to be employed. The IPP must be directed toward the acquisition of the behaviors necessary for the individual to function with as much self-determination and independence as possible and the prevention or deceleration of regression or loss of current optimal functional status.

**C. Program Implementation**

(42 CFR 483.440(d)). Each individual must receive a continuous active treatment program consisting of needed interventions and services in sufficient intensity and frequency to support the achievement of IPP objectives.

**D. Program Documentation**

(42 CFR 483.440(e)). Accurate, systematic, behaviorally stated data about the individual's performance toward meeting the criteria stated in IPP objectives serves as the basis for necessary change and revision to the program.

**E. Program Monitoring and Change**

(42 CFR 483.440(f)). At least annually, the comprehensive functional assessment of each individual is reviewed by the interdisciplinary team for its relevancy and updated, as needed. The IPP is revised as appropriate.

The federal survey team who conducted the annual survey at BHC were very complimentary to staff concerning Active Treatment for the residents.

**MISSOURI SENATE BILL 77-CHANGING MISSOURI MEDICAID PROGRAM TO GLOBAL WAIVER**

[https://www.senate.mo.gov/19info/BTS\\_Web/Bill.aspx?SessionType=R&BillID=159](https://www.senate.mo.gov/19info/BTS_Web/Bill.aspx?SessionType=R&BillID=159)



SB 77: Bill Activity – 12/1/2018 Prefiled 1/9/2019 First Read  
1/22/2019 Second Reading and Referred to Seniors, Families and Children Committee  
3/13/2019 Hearing 3/27/2019 Voted Do Pass

For the third year, Senator David Sater has introduced a bill to restructure MO HealthNet, Missouri’s Medicaid program.

Senate Bill 77 would make major changes to how MO HealthNet works.

One of the possible changes of SB 77 would be to change MO HealthNet to a block grant or per capita cap program, where a lump sum of money would be given to the state of Missouri at the beginning of the year, and the state would decide where to spend these funds.

Presently, needed services are rendered to those on Medicaid, and then these Medicaid expenses are reimbursed by federal funds to the state of Missouri at a rate of about 65%.

Capping and reducing federal financing for Medicaid could shift costs to states, beneficiaries, and providers.

**PARENT ASSOCIATION COMMENTS:**

Block grants and per capita caps for Medicaid could lessen the amount of funding from the federal government. Persons living in habilitation centers would be adversely affected, as cuts to federal reimbursements could lead state to Medicaid program cuts to eligibility and needed services.

Stay aware of any proposed Medicaid changes on the state and national level.

++++  
++++

**MO HEALTH NET AND MANAGED CARE**

Missouri’s Medicaid program is called MO HealthNet. Many of those enrolled in Missouri Medicaid are covered in Managed Care Programs. The contracts with the health care companies can limit what they are required to pay.

Currently, Missourians who are aged, blind or disabled, including those Missourians with developmental and intellectual disabilities served through the Missouri Department of Mental Health, receive services through the traditional MO HealthNet program, NOT in Managed Care.

There have been recent discussions to include persons with disabilities in a Managed Care Program.

Other states have changed to Managed Care of all of their Medicaid recipients with varying degrees of success or failure.

A transcript from the Department of Developmental Disabilities about Managed Care can be found at:

<https://dmh.mo.gov/dd/docs/docs/directorsdesktranscriptjanuary2019.pdf>

**PARENT ASSOCIATION COMMENTS:**

Including people with disabilities in a Medicaid Managed Care Program is another Medicaid issue to watch.

Concerns are that payment for current services could be lessened or eliminated in a Managed Care Program.

**NATIONAL STAFF SHORTAGE OF DIRECT SUPPORT PROFESSIONALS**

A qualified, competent and stable workforce of Direct Care Professionals (DSPs) is at the heart of providing quality supports and services for persons with intellectual disabilities (ID).

Currently there is a national staff shortage of DSPs, increasing the possibility of injuries, illnesses and abuse.

The President’s Committee for People with Intellectual Disabilities (PCPID) issued a 2017 report entitled “America’s Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy”.

[https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report\\_0.PDF](https://acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF)

According to excerpts of the report:

DSPs for persons with intellectual disabilities work in a range of settings, including family homes, people’s own homes, intermediate care facilities, small community residential group homes, community job sites, vocational and day training programs and others. They include full-time (70 percent) and part-time (30 percent) employees.

The pipeline of people entering the Direct Support Profession is not keeping pace with the number of DSPs needed by Americans with ID and their families.

The following factors have the greatest impact:

- (1) growth in the number of people with ID/DD who need and receive services
- (2) major shifts in the type of services desired and delivered to people with ID
- (3) steadily increasing longevity of people with ID/ DD
- (4) changing U.S. population demographics
- (5) changes in the overall U.S. labor force and economy
- (6) the failure to create an occupation of direct support with sufficient pay, benefits, training, career trajectories and status to recruit and retain a stable, skilled workforce to deliver on the promises made

**With annual DSP turnover rates nearing 50 percent nationally**, human services programs each year must recruit and train a number of new employees equal to more than half of their current workforce just to support their current clientele, and even more new DSPs to meet the growing demand of new entrants into human services.

Many DSPs are able to stay in their jobs only by working more than one job to have an adequate income for their families. These demands put DSPs and the people they support at greater risk because the DSPs are tired, potentially less alert and more susceptible to error while working.

One Recommendation is: The U.S. Department of Labor should engage the broader American workforce system to find solutions to this crisis by using community colleges and American job centers to develop and invest in career training and credentialing for Direct Support Professionals.

++++  
++++

Missouri habilitation center staffing is experiencing DSP staff shortages for the same reasons cited above. These are the staff who provide the day-to-day services needed by residents of habilitation centers some of which are: basic personal care and hygiene, toileting, bathing, meal preparation, health needs, transportation, employment, housekeeping, on-campus programming and recreation, and off campus activities.

Thank a BHC staff member for the dedicated, comprehensive care given to residents.

## **NATIONAL COUNCIL ON SEVERE AUTISM – NEW ORGANIZATION FORMED**

<https://www.ncsautism.org/>

The National Council on Severe Autism (NCSA) is a new organization formed by families to better advocate for persons with severe autism.

Jill Escher, president of the California-based organization, states: “This is a population with a set of issues that really needs to be heard.” Escher has two teenagers with severe autism, who she says have the functional capacity of preschoolers and depend on her for everything — every tooth brushed, every piece of clothing worn.

Amy Lutz, the organization’s secretary has stated: “We fully support self-advocates pursuing the support that they need, but this is completely separate,” she says.

The problem, she says, is that the autism spectrum spans a wide range of abilities and challenges.

“You have very mildly affected people on one end, who are college graduates, who are married with children,” she says. But on the other end of the spectrum there are “Adults who are in diapers and helmets and arm braces to prevent them from hitting themselves in the face hundreds of times an hour until they detach their own retinas.” (Lutz has written extensively about her son Jonah, who compulsively hit himself and pinched and bit his parents when he was younger and now, at 20, is prone to wander off with no notice.)

Matthew Siegel, associate professor of psychiatry and pediatrics at Tufts University in Boston, and board member of NCSA, says “We’re seeing this big wave of 20- to 30-something-year-olds with autism. A good portion of them are more severely affected and have big needs that the public system struggles to respond to in terms of housing, treatment, vocational opportunities and lifespan support.”

From the website of NCSA:

### **Guiding Principles**

**We believe in many "autisms."** Many millions of people have traits associated with autism. The NCSA, however, focuses on the burgeoning population of children and adults affected by severe forms of autism or related disorders. This population includes those who, by virtue of any combination of cognitive and functional impairments, require continuous or near-continuous, lifelong services, supports, and supervision. Individuals in this category are often nonverbal or have limited use of language, have intellectual impairment, and, in a subset, exhibit challenging behaviors that interfere with safety and well-being.

**We face an urgent, mounting crisis.** Due to its rapid increase in prevalence and the severity common in this disability, severe autism has developed into an urgent public health and social services crisis. Pragmatic policy reform to address the lifespan needs posed by severe autism-associated disability is needed, including empowering the nonprofit sector to provide a full continuum of programs, facilitating family and private investments in a wide array of housing and long-term care options, and crafting more efficient federal and state funding mechanisms.

**We believe in the importance of treatment and intervention.** Individuals and families affected by severe autism and related neurodevelopmental disabilities often suffer very low quality of life due to disruptive and dangerous behaviors and emotional, physical, and financial stress. Innovation in treatment across the lifespan is urgently needed, both to improve autism-associated functional deficits and also the variety of co-morbidities and health conditions affecting the majority of people with severe forms of autism.

### **What We Do**

We are committed to improving the long-term welfare of individuals, families and caregivers affected by severe forms of autism and related neurodevelopmental disorders. To that end, we:

- **Educate the public** about these disabilities, and how they require special attention and services.
- **Provide a platform** for think tanks and serious discourse addressing policy and services.
- **Educate policy makers** about the impact of legislation and policy on our vulnerable, growing, and often overshadowed population.
- **Promote research** into therapeutics, neurobiology, and causes of severe forms of autism and related disabilities.
- **Promote acceptance and awareness** of individuals, families, and caregivers affected by severe forms of autism by giving voice to their realities and needs.



**VOR UPDATES ON FEDERAL LEGISLATION**  
[www.vor.net](http://www.vor.net)

**THE DISABILITY INTEGRATION ACT (DIA) SENATE BILL 117, HOUSE BILL 555**

Senator Chuck Schumer has again introduced The Disability Integration Act (DIA), Senate Bill 117.

While the intention of the bill is to provide services for all people with intellectual and developmental disabilities, serious flaws in the bill would put persons who are the most disabled in harm's way.

- The bill would eliminate existing services provided in facilities like habilitation centers.
- These individuals would be forced out of their homes into more scattered settings throughout the community.
- The current Home and Community Based system is already riddled with problems, especially in the lack of reporting of critical incidents of abuse and neglect.
- Community homes many times provide fewer services, lower staffing ratios, and lower standards of care.
- The bill would also be prohibitively expensive. It would severely inflate the federal Medicaid system and strain state Medicaid budgets.
- There are not enough Direct Support Professionals, nurses, and other medical professionals and auxiliary workers to enact the scope of the bill.

**TAKE ACTION**

Contact your federal legislators to reject this bill, and find responsible ways to improve services for all people with intellectual and developmental disabilities including those who need the high level of care available in facilities like Missouri habilitation center homes.

For a sample letter go to [www.vor.net](http://www.vor.net)

To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000, or go to: [www.mo.gov](http://www.mo.gov)



Look for your federal U.S. senators and representatives.

++++  
++++

**VOR - OUR NATIONAL VOICE TO ADVOCATE FOR OUR FAMILY MEMBERS**  
[www.vor.net](http://www.vor.net)

VOR is a national organization that advocates for high quality care and human rights for people with intellectual and developmental disabilities.

Every day VOR is diligently working on the local, state and federal levels to educate about the needs of individuals who are intellectually disabled, especially those who are severely affected.

**Join VOR – our national voice to maintain a choice from a full continuum of care for persons with intellectual disabilities. \$45 per year per individual; \$200 per year per family organization; or \$250 per year per provider/professional organization**  
**Send completed form with payment to: (checks made out to “VOR”)**

VOR  
 836 S. Arlington Heights Rd., #351  
 Elk Grove Village, IL 60007  
 Name: \_\_\_\_\_  
 Address: \_\_\_\_\_  
 City: \_\_\_\_\_  
 State: \_\_\_\_\_ Zip \_\_\_\_\_  
 Home Phone: \_\_\_\_\_  
 E-Mail: \_\_\_\_\_

**Gifts to VOR are tax deductible to the fullest extent of the law. TOLL FREE 877-399-4867**  
**WWW.VOR.NET**

**YOU CAN BE A PART OF THIS IMPORTANT WORK. BECOME A MEMBER OF VOR.**

TRIBUTE FUND FORM (please print)

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

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

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

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

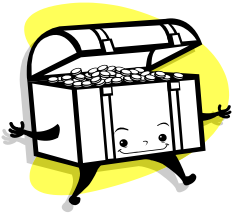
(address) \_\_\_\_\_

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

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

MAKE CHECKS OR MONEY ORDERS PAYABLE TO "BHC Parents Association"

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

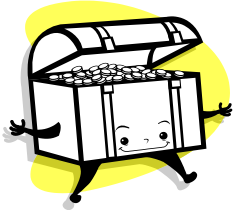


**THE HIDDEN TREASURE SHOP  
NEW HOURS!! BEST THRIFT SHOP PRICES!!**

**BLDG #1901** FIRST BUILDING ON THE LEFT AS YOU ENTER BHC CAMPUS.

**WEDNESDAYS, 11 A.M. TO 2 P.M. AT BHC**

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



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

FORWARDING AND ADDRESS  
CORRECTION REQUESTED