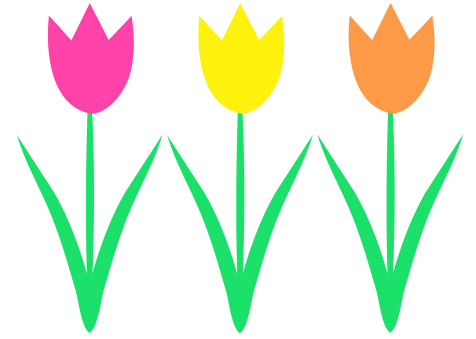


**PARENTS ASSOCIATION  
BELLEFONTAINE HABILITATION CENTER  
10695 BELLEFONTAINE ROAD  
ST. LOUIS, MO 63137**

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



**NEWSLETTER    MAY 2018**

PARENTS ASSOCIATION MEETING  
SUNDAY, MAY 20 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 20, 2018**

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

**2018 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!**

**MAY 20**

**AUGUST 12**

**NOVEMBER 11**

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**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.

**The annual federal survey of BHC** can occur any time in the next few months. There are over 500 regulations that are reviewed for Medicaid funding eligibility. These regulations concern the safety, health, and support for BHC residents.

**Employee training for the newly required Emergency Operations Plan has begun.** These new requirements will become part of the federal annual survey for Medicaid funding.

**Work on the replacement of the heating and cooling system** may be completed sometime in April.

**The gym in the Multipurpose Building** is being updated with a new floor and new bleachers.

**The 2018 Missouri Legislative Session** ends on May 18, 2018. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to [www.mo.gov](http://www.mo.gov).

**House Bill 1553, introduced by Rep. Jim Neely,** revises Missouri guardianship laws.

**The 2018 VOR Annual Conference and Congressional Visits** will be from June 8 – June 13. 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 – some or all of the days – you can be a voice for intellectually disabled persons, especially residents of BHC. For more information go to [www.vor.net](http://www.vor.net)

**Keep informed. Take action.**      Mary A. Vitale, President, Bellefontaine Parents Association

**TRIBUTE FUND**

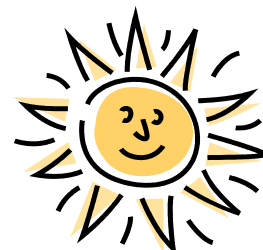
Celebrate a birthday or anniversary, offer get well wishes or congratulations, remember a loved one by sending in a tribute - support the residents at Bellefontaine Habilitation Center. A few examples of the use of funds are: annual picnic, Christmas gifts and decorations, birthday cakes and presents,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

<b><u>DONOR</u></b>	<b><u>RECIPIENT</u></b>	<b><u>OCCASION</u></b>
Chris Bomze		donation
Betty Coll	Steve Vitale	Get well wishes
Evelyn Dennes	Tanya Newsome	In memory of Michelle Newsome
Ruth Hayden	Izella Moore	In memory of Richard Moore
Lee & Jackie Kearney		donation
Mickey Slawson	Izella Moore	In memory of Richard Moore
Leslie Terrebonne	Izella Moore	In memory of Richard Moore



**FUNDS APPROVED BY PARENTS ASSOCIATION BOARD**

- \$ 350.00 Valentine Dance decorations, Valentine treats
- \$ 350.00 Easter Dance decorations, Easter treats
- \$ 200.00 Household goods, Home 1807



THANKS TO THE BIG HEARTS AND HARD WORK OF THE VOLUNTEERS  
AT THE HIDDEN TREASURE THRIFT SHOP.

ALL THE SHOP PROCEEDS GOES TO BENEFIT BHC RESIDENTS.

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**PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2018**

Dues are \$5.00 a year. Make checks payable to “**BHC Parents Association**”.

NAME \_\_\_\_\_

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

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

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

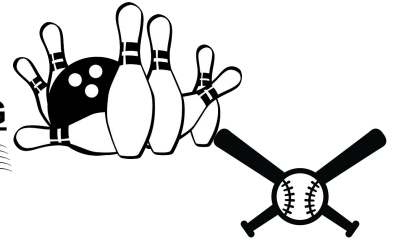
PHONE NUMBER \_\_\_\_\_

NEW MEMBER  yes  no \_\_\_\_\_

**If you are a new member, please let us know for mailing the newsletter.**

**Mail to: PARENTS ASSOCIATION 10695 BELLEFONTAINE ROAD  
ST. LOUIS, MO 63137**

**WHERE, OH WHERE HAVE BHC RESIDENTS BEEN? WINTER/SPRING**



**Valentine Dance**

**Shopping:** Goodwill, Kmart, Walmart, Beauty Supply, Gas Station, Five Below, GenX, Family Dollar, V Stock, Mid River Mall, Game Stop, Aldi's, Target, Quik Trip, Shop n Save, Michaels, Kohls, Payless, Dirt Cheap, Best Buy, Shoe Carnival, Burlington Coat Factory, Dierbergs, TJ Maxx, Dollar Tree

**Out to Eat:** Canes, Hooters, Rice House, Culvers, White Castle, Fazoli's, Las Fuentes, 54<sup>th</sup> Street Grill, Steak n Shake, Sonic, 5 Guys burgers, Dennys, Churchs Chicken, Taco Bell, Imos, Long John Silvers, Captain D's, Subway, Qudoba, Pizza Hut, Chinese, Panda Express, Dairy Queen, Bandanas, St. Louis Fish & Chicken, Hibachi Grill, Sweetie Pies, Hometown Buffet, Burger King, McDonalds, Pironnes Pizza, Sonic, Smoothie King, Ted Drewes, Crown Candy, Pasta House, Fritz, Andys

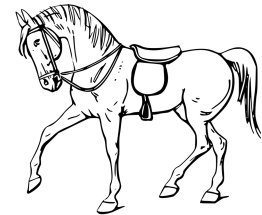
**Other:** St. Louis Auto Show, Great Clips, Olivette Bowl, Union Tabernacle Church, Jack of all Fades, Mills Mall Movies, Regal Theater, West County Mall, South County Mall, Thrift Store, Galleria Mall, Cardinal Baseball Game, Blues Hockey Game

Residents at BHC are enjoying a variety of activities in the community, and have a safe, healthy, caring home to return to. Thanks to staff for helping residents plan and participate in so many activities.

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**APRIL WAS AUTISM AWARENESS MONTH**

The following article excerpt shows the positive benefits of being around animals for persons on the autism spectrum.



"New Research Finds Animals May Help Kids on the Spectrum"  
by Rita Giordano, Philly.com/TNS | January 19, 2018  
<https://www.disabilitycoop.com/2018/01/19/new-research-animals-spectrum/24611/>

Sabrina Opstbaum wasn't expecting miracles when she started taking her daughter Reegan to the Barn at Spring Brook Farm, an animal-assisted intervention program for children with special needs in West Chester. Like many kids on the autism spectrum, Reegan didn't seem to connect with people, but she always enjoyed the company of animals.

After two years of weekly visits and summer camp with Annabelle the goat, Sugar the sheep, Dreamer the miniature horse, and their other barnyard cohorts, Reegan, now 8, is in many ways a changed little girl.

"She's become less aggressive," Opstbaum said. "She's in a calm mood when she's there, and it even carries over into school the next day, sometimes two days after. She's just more calm. And happy."

What made the difference?

"I honestly think it's the fact that the animals don't expect anything from her," Opstbaum said. "Their calm transfers over to her. With people, we're always placing demands. With animals, they're not asking for anything. It's just, 'Be with me.'"

A growing body of research has uncovered evidence that animal-assisted interventions (AAI) may help improve the lives of people with autism by addressing some of the disorder's more difficult symptoms.

Among the studies' key findings are increased social interaction and decreased anxiety — classic autism earmarks that increase kids' isolation...

\*\*\*\*\*

**MO ABLE SAVINGS ACCOUNTS**



MO ABLE is a program that allows Missourians living with disabilities to save and invest through tax-free savings accounts without losing eligibility for federal programs like Medicaid and Supplemental Security Income (SSI). However, Medicaid does have the ability to reclaim money remaining after an account holder dies to pay for benefits disbursed to them.

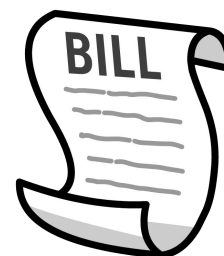
This Missouri program began last year in April. To learn the most current information about this new program go to the MO ABLE website: <https://www.moable.com>

**MISSOURI LEGISLATION TO WATCH**

**Missouri House Bill 1553** introduced by Rep. Jim Neely, modifies provisions relating to guardianship and conservatorship proceedings.

<http://www.house.mo.gov/bill.aspx?bill=HB1553&year=2018&code=R>

Depending on what is passed, guardianship rights could be weakened.



**PARENT ASSOCIATION COMMENTS:**

Updating Missouri guardianship laws is a very worthwhile endeavor.

However, upon review of the proposed changes included in House Bill 1553, families have concerns about some of the particular wording in Section 475.359, page 37, lines 39-41.

Lines 39-41 state: (3) “Assure that the ward resides in the best and least restrictive setting reasonably available. The guardian shall give priority to home or community-based settings if not inconsistent with the ward’s goals and preferences.”

The concern is that a guardian should not be forced by law to give priority to home or community-based settings. This conflicts with federal and state law protecting the right of the guardian to have **choice** from all available living options, not giving preference to any of them. The needs of the wards must be the priority in making decisions concerning their welfare.

The proposed change to require the guardian to give priority to home or community-based settings differs from current federal and state law as shown in the following quotes.

**The Code of Federal Regulations**, 441.302 42 CFR Ch. IV, states:

“(d) *Alternatives*—Assurance that when a recipient is determined to be likely to require the level of care provided in a hospital, NF, or an ICF/MR , the recipient or his or her legal representative will be

(1) Informed of any feasible alternatives available under the waiver; and

(2) given the **choice** of either institutional or home and community-based services”

**The Missouri Department of Mental Health, Division of Developmental Disabilities Waiver Manual** states on page 7:

“When it is determined that a person needs the level of care provided in an ICF/DD, the support coordinator informs the person or a legal guardian of any feasible alternatives available under the waiver and gives the person the **choice** of either institutional or home and community-based waiver services.

We suggest the following language for lines 37-41, page 37 that more closely mirrors current federal and state law, and would better consider the needs of the ward as the priority in making decisions.

**“Assure that the ward resides in the best and least restrictive setting. The guardian shall be informed of any feasible alternatives available under a waiver, and shall be given the choice of either institutional or home and community-based waiver services.”**

**Missouri Senate Bill 562**

[http://www.senate.mo.gov/18info/BTS\\_Web/Bill.aspx?SessionType=R&BillID=69471947](http://www.senate.mo.gov/18info/BTS_Web/Bill.aspx?SessionType=R&BillID=69471947)

Introduced by Senator David Sater, SB 562 proposes to change the way Medicaid works in Missouri by applying for a global waiver, using block grants for federal funding. SB 562 has had no action since January.

**PARENT ASSOCIATION COMMENTS:**

Block grants for Medicaid could lessen the amount of funding from the federal government. Stay aware of any proposed Medicaid changes on the state and national level.

**HOME AND COMMUNITY BASED SERVICES (HCBS) WAIVER HOME OVERSIGHT LACKING OVER THE DECADES - NEED FOR INCREASED OVERSIGHT**

The Medicaid Home and Community Based Services (HCBS) waiver program was established with the passage of section 2176 of the Omnibus Budget Reconciliation Act (OBRA) of 1981. Section 2176 created section 1915(c) of the Social Security Act, which authorized States to request the option of providing home and community-based alternatives to institutional care.

Because the 1915(c) waivers were created to offer alternatives to institutionalization, program regulations require HCBS to be offered only to those who are eligible for institutional placement (42 C.F.R. 440.180).

The 1915(c) HCBS waivers are required to be, by statute, cost-neutral, requiring the States to keep waiver costs at or below those of comparable institution-based service.

The beneficiaries served by these programs are among Medicaid's most vulnerable.

There are 6 Assurances that states must comply with to receive and renew a waiver

1. **Level of Care:** Participants enrolled in the HCBS waiver meet the level of care criteria consistent with those residing in institutions.
2. **Service Plan:** A person's needs and preferences are accurately assessed and reflected in a person-centered service plan.
3. **Qualified Providers:** Agencies and workers providing services are qualified.
4. **Health and Welfare:** Participants are protected from abuse, neglect and exploitation and get help when things go wrong or bad things happen.
5. **Financial Accountability:** A state Medicaid Agency pays only for services that are approved and provided, the cost of which does not exceed the cost of a nursing facility or institutional care on a per person or aggregate basis (as determined by the state).
6. **Administrative Authority:** The state Medicaid Agency is fully accountable for HCBS waiver design, operations and performance.

HCBS waivers are initially granted for 3-5 years with States documentation of the 6 Assurances from the State. Upon request for renewal of the waiver for another 3-5 years, an onsite review is recommended.

States are responsible for monitoring the quality of their own programs and for developing their own systems to continuously monitor whether the State is meeting the assurances. Monitoring can include beneficiary surveys, record reviews, or onsite visits.

**For many years, federal agencies have raised concerns about the quality of care provided under these waiver programs. Lack of oversight has been a consistent problem for decades.**

**In 2003**, the Government Accountability Office found that more than 70 percent of the programs it reviewed had problems with quality of care, such as failure to provide necessary services, weaknesses in beneficiaries' service plans, and inadequate case management.

<https://www.gao.gov/new.items/d03576.pdf> 2003



**In 2012**, a report from the Department of Human Services, Office of Inspector General states that adequate systems to ensure quality of care are lacking in many states.

<https://oig.hhs.gov/oei/reports/oei-02-08-00170.pdf> 2012



**In 2018**, another report has been issued by U.S. Department of Health and Human Services Office of Inspector General (OIG), Administration on Community Living and the Office for Civil Rights.

**“OIG found that health and safety policies and procedures were not being followed. Failure to comply with these policies and procedures left group home beneficiaries at risk of serious harm. These are not isolated incidents but a systemic problem – 49 States had media reports of health and safety problems in group homes.”**

<https://oig.hhs.gov/reports-and-publications/featured-topics/group-homes/group-homes-joint-report.pdf> 2018



**ARTICLE ON MOST CURRENT REPORT ON QUALITY OF CARE IN WAIVER HOMES**

“Government Watchdog Warns Of Group Home Dangers” by Michelle Diamant | January 18, 2018  
<https://www.disabilitycoop.com/2018/01/18/government-group-home-dangers/24603/>

Injuries, serious medical conditions and even deaths of those with developmental disabilities living in group homes often are not looked into and go unreported, federal investigators say.

An audit of three states found that officials routinely failed to follow up on incidents ranging from head lacerations to loss of life in violation of federal and state policy. The issues are believed to be systemic affecting people with developmental disabilities residing in group homes across the country.

That’s according to a [joint report](#) issued Wednesday from the U.S. Department of Health and Human Services Office of Inspector General, Administration on Community Living and Office for Civil Rights, which is recommending policy changes.

The report stems from a 2013 [request](#) by U.S. Sen. Chris Murphy, D-Conn., who was alarmed by newspaper reports of widespread abuse and neglect of group home residents in his state. After the inspector general’s office found serious problems in its review of Connecticut, the office conducted similar audits of Massachusetts and Maine.

In each state, investigators identified emergency room visits from group home residents, then determined if the incidents were reported to the state and, if so, what action the state took.

The inspector general’s office found that group homes often failed to report incidents to state officials. But even when states knew, up to 99 percent went unreported to law enforcement or other authorities for investigation.

“Each state was somewhat unique, but what was similar across the states was that there were gaps in policies and procedures so that when an incident occurred, they could make sure that it was identified, investigated, corrected and reported,” said Megan Tinker, senior advisor for legal review at the Office of Inspector General and an author of the report.

Aside from the three states that were audited, investigators said that recent media reports from 49 states citing health and safety problems in group homes suggest the issues are pervasive. The Office of Inspector General has additional audits underway or planned in another six states, Tinker said.

Citing the “magnitude of the danger for beneficiaries,” the Office of Inspector General worked with the Administration for Community Living and the HHS Office for Civil Rights and other federal entities to develop recommendations for the Centers for Medicare and Medicaid Services and states to address the holes in existing policies and procedures.

The report released this week is a culmination of that work and includes model practices for states to develop better oversight. In addition, the Centers for Medicare and Medicaid Services should take steps to help states address problems by forming a “SWAT” team and taking action when problems are identified in order to ensure the safety of group home residents, the recommendations indicate.

“CMS is working directly with the three states specifically examined by the OIG, and is working with department partners to distribute tools, information and any other necessary assistance to all states to ensure that quality care is being provided to all Medicaid beneficiaries,” the Centers for Medicare and Medicaid Services said in a statement to Disability Scoop. “The suggestions found in this report are being carefully examined for further action by the agency.”

Despite the problems identified, Tinker said many group homes are great places.

“If people are looking at a group home for their loved ones, we think it’s important to spend time at the group home and to ask questions and make sure it has the right policies and procedures in place,” she said. “What do they do if something goes wrong?”

**PARENT ASSOCIATION COMMENTS:**

Residents in habilitation centers are covered by over 500 federal regulations to assure their quality of living. These extensive Annual Surveys are completed by on-site observations, and are not announced ahead of time. A review of all resident documentation is also part of the Annual Survey.

Every person with intellectual disabilities deserves the highest level of oversight. Continued reports of lax oversight in waiver homes is deeply worrisome and inexcusable. There is a great need for stricter requirements for waiver homes to maintain the quality of life for the residents. Families should always be vigilant about the living environment of their loved ones with intellectual disabilities, no matter where they live.



**NEW LAW AFFECTS SOCIAL SECURITY REPRESENTATIVE PAYEE PROGRAM**

<https://www.congress.gov/115/bills/hr4547/BILLS-115hr4547ih.pdf>

Do you receive Social Security payments for your disabled loved one? New rules are now in effect.

In April, the *Strengthening Protections for Social Security Beneficiaries Act of 2018* (H.R. 4547) was signed into law. It was introduced by Ways and Means Subcommittee Chairman Sam Johnson (R-TX) and Ranking Member John Larson (D-CT)

The new law makes numerous changes to the program with the intent to have better oversight.

Representative payees should be aware of these changes, especially the new role of the state Protection and Advocacy (P&A) Systems. P&As will be involved in reviewing how representative payees are carrying out their duties.

**Strengthening Protections for Social Security Beneficiaries Act of 2018**

- Oversight of representative payees will be strengthened by increasing the number of performance reviews of payees, requiring additional types of reviews, and improving the effectiveness of reviews.

The Protection and Advocacy system in each State will be awarded annual grants from Social Security to review representative payees, including reviews in response to allegations or concerns about the performance or suitability of the payee. A protection and advocacy system may refer beneficiaries to other programs or services as the protection and advocacy system considers appropriate.

- The requirement to file the annual accounting form for representative payees who are parents living with their children or who are spouses will be eliminated. Lawmakers and Social Security say the annual accounting paperwork is expensive to process and rarely reveals misuse of funds.
- The most vulnerable beneficiaries will be protected through improved information-sharing by requiring the Social Security Administration (SSA) to identify whether a beneficiary is in foster care and reassess whether the payee is appropriate, and by directing the SSA to study how better to coordinate with Adult Protective Services and with state guardianship courts.
- Beneficiaries will be allowed to make a designation of their preferred payee in advance.
- There will be a limit to overpayment liability for children in the child welfare system.
- It will ensure that no beneficiary has a barred payee by codifying the policy that bans individuals with certain criminal convictions from serving as payees (including individuals currently serving as payees) and prohibiting individuals who have payees from serving as a payee for others.

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**VOR MEMBERS SUBMIT TESTIMONY IN HEARINGS WITH HOUSE JUDICIARY COMMITTEE EXAMINING CLASS ACTION LAWSUITS AGAINST INTERMEDIATE CARE FACILITIES FOR INDIVIDUALS WITH INTELLECTUAL DISABILITIES**



The House Judiciary Committee convened on March 6th, 2018 to examine class action lawsuits against ICF's/IID. The issue before the committee centered on the fact that these lawsuits have been conducted without the knowledge of stakeholders (residents, parents, and guardians) and without allowing notification of their right to opt-out of the suit. The committee also looked into the question of whether these suits are initiated with a bias against ICF's and with the goal of ultimately forcing their closure. The sub-committee hearings were chaired by Rep. Steve King (R-IA) at the request of House Judiciary Committee Chair Bob Goodlatte (R-VA).

Testimony on behalf of VOR was provided by:

- Martha Bryant - Mother and RN, BSN, of Virginia
- Caroline Lahrmann - Mother, President of Disability Advocacy Alliance and VOR Ohio State Coordinator
- Peter Kinzler - Father and longtime VOR member, Legislative Committee Chair, who spent most of his professional career working on Capitol Hill.

Opposing testimony was given by Alison Barkoff, Director of Advocacy at the Center for Public Representation, formerly of the Department Of Justice under Tom Perez.

**Go to [www.vor.net](http://www.vor.net) to watch or read the excellent family testimony given. Your time will be well spent.**

TRIBUTE FUND FORM (please print)

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

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

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

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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