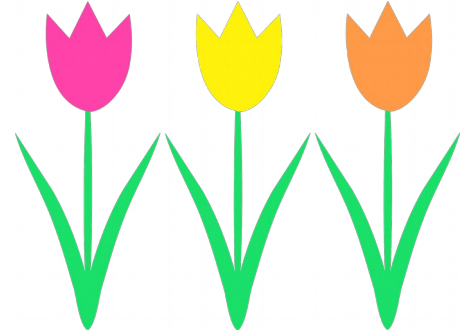


**PARENTS ASSOCIATION
BELLEFONTAINE HABILITATION CENTER
10695 BELLEFONTAINE ROAD
ST. LOUIS, MO 63137**

PHONE 314-340-6002 Thrift Shop
PHONE 314-264-9100 BHC Switchboard
WEBSITE www.parentsassociationbhc.com

NEWSLETTER MAY 2016



PARENTS ASSOCIATION MEETING
SUNDAY, MAY 15, 2016 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 15, 2016

NOTE: NEW MEETING BUILDING

2:00 P.M. in the Administration Bldg. Room #10

2016 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!

MAY 15

AUGUST 14

NOVEMBER 13

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

Our Parent Newsletter is online at www.ParentsAssociationBHC.com!! Pass it along to friends, family, and political leaders.

The 2016 Legislative Session began on January 6 and ends on May 13, 2016. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to www.mo.gov. Also at www.mo.gov, choose Government, then Legislative to follow actions on bills and listen to live debates.

House Bill 2778 was introduced by Representative Jim Neely. HB2778 contains the proposed revisions of the Missouri guardianship laws. **House Bill 1565**, introduced by Representative Kevin Engler, has to do with raising the asset limit to be eligible to receive Medicaid benefits.

The merging of the Higginsville and Marshall Habilitation centers is ongoing. The Marshall center will be closed, with some residents moving to the Higginsville center, and some moving to the community.

Habilitation centers are good homes for residents. They are successful, stable, and sustainable, giving comprehensive, consistent, and cost-effective care to the residents

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

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 Craig
 Roseanne Dickey
 Mr. & Mrs. Donovan
 Mr. & Mrs. Hizer
 Joan Murphy family
 Mr. & Mrs. Ruzensky

Cheryl Kaczmarek
 Mary Jane Gamache

donation
 in memory of Marty Kaczmarek
 donation
 in memory of John Gamache
 in memory of Page Ellen Murphy
 in memory of George Minstermann

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FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$ 300.00 Valentine candy, treats
 \$ 300.00 Easter candy, treats
 \$ 200.00 Household goods, Home 1803
 \$ 150.00 Household goods, Home Apt. A



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SPRING RESIDENT ACTIVITIES

Recent social activities on and off campus enjoyed by BHC residents include:

On campus:

Movies, volleyball, basketball, Wii games, bingo and dances in the gym

Church services on Tuesday's and Saturday's

Director's Creativity Showcase art projects

Valentine Dance with a band and treats (cake, pudding, jello, cookies, punch)

Valentine treats – everyone received a bag of treats on Valentine's day

Black History Program

Easter Dance with a DJ and treats (cake, pudding, jello, cookies, punch)

Easter treats – everyone received a bag of treats for Easter

The Music man plays his guitar in the music room every Wednesday and Thursday morning

Off Grounds:

Disney on Ice Shriners Circus Madea on the Run Out to eat Union Station

Shopping at the different malls and stores in the area Beauty and Barber shops

Ambush soccer game Special Olympics Track & Field events (April 30th)



THANKS TO STAFF for assisting residents in planning and enjoying this wide variety of activities.

MO HOUSE BILL 2778 - PROPOSED CHANGES TO MISSOURI'S GUARDIANSHIP LAW

www.house.mo.gov/billsummary.aspx?bill=HB2778

Representative Jim Neely introduced House Bill 2778 that would put into law the revisions of the Missouri guardianship law proposed by Missouri’s Working Interdisciplinary Network of Guardianship Stakeholders (MO-WINGS).

The MO-WINGS task force used the National Guardianship Summit Standards and Recommendations as a guideline to Missouri revisions. www.naela.org/NGN

Some of the changes are reasonable.



However, Parent Association concerns continue to be:

1: the new wording (page 75, line 40-41) that states:

(3) “The guardian shall give priority to home or community-based settings when not inconsistent with the ward’s goals and preferences;”

COMMENT: The guardian should not be limited in this way. The needs of the wards must be the priority in making decisions concerning their welfare. This wording should be deleted.

2: the repeated necessity of including the ward that has been determined by the courts to be “incapacitated” in the decision making process

COMMENT: If one has been declared by the courts as incapacitated how can that person participate in decision making? If one is indeed capable of decision making then maybe a guardianship is not needed. It would be better to keep the old wording of “in the best interest of the ward”.

Actions of April 20, 2016

Date	Jrn Pg	Activity Description
3/15/2016	H 1294	Introduced and Read First Time (H)
3/16/2016	H 1308	Read Second Time (H)
3/30/2016	H 1419	<u>Referred: Civil and Criminal Proceedings(H)</u>

HB 1565 ASSET LIMIT INTRODUCED BY REP. KEVIN ENGLER

www.house.mo.gov/billtracking/bills161/sumpdf/HB1565P.pdf

HB 1565 -- PUBLIC ASSISTANCE

COMMITTEE OF ORIGIN: Standing Committee on Children and Families

This bill increases the asset limits for MO HealthNet permanent and totally disabled claimants, MO HealthNet blind claimants, and MO HealthNet aged claimants starting in fiscal year 2018, from no greater than \$1,000 for individuals to \$2,000 and from no greater than \$2,000 for married couples to \$4,000. For each fiscal year after 2018 through 2021, those asset limits will be increased \$1,000 and \$2,000 respectively so that by fiscal year 2021 the limit for individuals will be \$5,000 and for married couples \$10,000. Beginning in fiscal year 2022, these limits must be modified to reflect any cost-of-living adjustments. The bill excludes from asset limit calculations medical savings accounts and independent living accounts as defined in the Ticket to Work Health Assurance Program.

Actions as of April 20, 2016:

Date	Activity Description
4/12/2016	Public Hearing Scheduled (S) - Thursday, April 14, 2016, 8:30am, Senate Lounge
4/14/2016	Public Hearing Held (S)
4/14/2016	Executive Session Held (S) - Voted do pass

APRIL WAS AUTISM AWARENESS MONTH

According to the Center for Disease Control & Prevention (CDC, www.cdc.gov/), 1 in 68 children are diagnosed with autism. These persons may need a lifetime of services. Families need ongoing assistance to make educated choices about needed services at every age of the individual with autism.

Missouri has an Office of Autism to help families find appropriate services for persons diagnosed with some level of autism. www.dmh.mo.gov/dd/autism

Madison House Autism Foundation is a national organization providing education about the autism spectrum and advocating for services for persons with all levels of autism, including those with severe disabilities needing a high level of support services. www.madisonhouseautism.org

Autism Treatment Network includes 14 sites across the United States and Canada. The Autism Treatment Network has hospitals, physicians and researchers to assist families. Two of these are located in Missouri:

University of Missouri Columbia, MO
Contact: Alicia Curran
Phone: (573) 884-7544
CurranA@health.missouri.edu

Knights of Columbus Child Development Center at SSM Cardinal Glennon Children's Medical Center and Saint Louis University School of Medicine St. Louis, MO
Contact: Rolanda Maxim Gott
Phone number: 314-577-5609
Email: maximr@slu.edu

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Individuals diagnosed to be on the autism spectrum have a wide variance of how autism affects them. Some will be able to graduate from college and have a work career. On the other end of the spectrum are those persons who will need lifelong, high level support services.

Difficulties for families looking for appropriate services, especially for those with severe autism, is emphasized in the article below. This article is from Ohio but could be from any state in the country. This article shows the continued need for a full continuum of services for persons with an intellectual disability.

Parents Frustrated by Lack of Residential Treatment Options
www.disabilitycoop.com/2016/04/01/parents-residential-treatment/22121



by Rita Price, The Columbus Dispatch/TNS | April 1, 2016

COLUMBUS, Ohio – The Steffens can’t go on a family outing to a park. Or stay with out-of-town relatives. Or, if 11-year-old Andrew is along, even stop by the grocery.

“We’ve withdrawn from the community,” said Andrew’s mom, Jamie Steffen.

And home isn’t exactly a refuge. It sometimes feels more like a holding cell, with alarms and locks on all the windows and doors to help keep Andrew, who has severe autism, from barreling out and causing harm to himself or others.

The Steffens are among an untold number of families doing their best to care for volatile children whose developmental disabilities and mental-health disorders have led to behavioral crises. Even when doctors say residential treatment is desperately needed – Andrew’s developmental pediatrician has made that recommendation, Steffen says – parents can face a near-impossible struggle to find, or pay for, a suitable center.

A last-ditch effort to save central Ohio’s only short-term residential center for children with severe autism and behavioral problems failed late last year, and the 14-bed Elijah Glen Center remains closed.



Parents Frustrated by Lack of Residential Treatment Options, continued.

Steffen, who lives in Montgomery County near Dayton, said she and her husband can't find anything available in the state. "I might have to accept a reality where I only see him once a month," she said, her voice breaking as she spoke of treatment for Andrew in Indiana, Virginia or Florida.

Still, Steffen said, she is grateful that her husband's military health insurance covers at least some in-home and residential care. Child-welfare advocates say families who can't pay for behavioral-health treatment sometimes wind up relinquishing custody to public child-welfare agencies to obtain it.

Medicaid covers behavioral-health services but won't provide for the room-and-board portion of expensive residential treatment. State-run developmental centers provide residential care for adults with disabilities, not minors in crisis.

"The one thing I really want to bring attention to is that if we were talking about a kid with a brain tumor, we would not be asking parents to send their kids miles away for months, nor would we be asking them to surrender custody," Steffen said. "I know we've made progress with the (mental-health) parity law. But it's not equal."

Ohio needs both a holistic approach and a funding mechanism to support behavioral-health treatment for children, said Angela Sausser, executive director of the Public Children Services Association of Ohio.

In 2013, she said, six in 10 children in the custody of county agencies across the state came into care for reasons other than abuse or neglect. Many have intense mental-health needs and disabilities, including autism, and county agencies are able to use foster-care funds to pay for care.

"There are hard choices that parents are making right now," Sausser said.

A joint legislative committee is studying the problems surrounding care of so-called multi-system youth, or those who need services from more than one system – mental health and addiction, child protective services, developmental disabilities and juvenile courts.

The committee is to make a series of recommendations, including ways to provide adequate funding and services.

"What's great is that we have a panel of legislators really listening," said Marla Root of Step by Step Academy, an autism center whose Worthington campus includes the closed Elijah Glen Center. "They're asking good questions."

Addressing the funding problem could lead to growth in the field, advocates say. Franklin County Residential Services, a nonprofit that has been providing services and residential support for people with developmental disabilities for more than 30 years, tried to help with the Elijah Glen Center but so far hasn't been able to develop a viable plan

Root says the center struggled and closed within a year because not enough families could find ways, short of surrendering custody, to pay for care. That leaves families such as the Steffens wondering how far they will have to go to get consistent help. The stress in their home, meanwhile, is enormous.

"When he was younger and had an outburst, I could control it. Those days are long gone," Steffen said of her nonverbal son, who weighs 125 pounds. He doesn't understand how his actions – head-butting, slapping, shoving – affect others. He regularly tries to push his 15-year-old sister down the stairs.

Steffen said her daughter is kind and uncomplaining. But the parents wonder whether they've reached a point "where we're not just asking her to love and accept her brother with autism. We're almost asking her to accept being abused."

The couple has even talked about sending her to grandparents. "Is that the right thing? To try to save one? But that still wouldn't solve his problems," Steffan said, crying softly. "It's a mess. It really is."

CLEARLY, THE NEED FOR MORE HOUSING CHOICES, NOT LESS, WILL CONTINUE

WORKFORCE INNOVATION AND OPPORTUNITY ACT AND SHELTERED WORKSHOPS

Signed into law in 2014, the Workforce Innovation and Opportunity Act (WIOA) could impact every sheltered workshop in Missouri.

Part of this law prohibits individuals age 24 and younger from working jobs that pay less than the federal minimum of \$7.25 per hour unless they first try vocational rehabilitation services.

Some information connected with WIOA is critical of sheltered workshops and subminimum wages allowed under Section 14(c) of the Fair Labor Standards Act.

A major concern involves the push to eliminate workshops entirely.

Where workshops have been reduced or eliminated, many workers with disabilities do not find community employment or work hours are greatly lessened. Some end up staying home with little to do.

Leann Fox, ACCSES (www.accses.org) Director of Government Relations has stated:

“While there are some positive recommendations included in the Interim Report, we believe that any recommendations on the elimination or phase-out of sheltered workshops and Fair Labor Standards Act (FLSA) 14(c) Certificate Programs is systemically flawed.”

INDIVIDUALS WORKING IN SHELTERED WORKSHOPS AND THEIR FAMILIESS VALUE THE WORKSHOP ENVIRONMENT WHERE MEANINGFUL WORK IS ACCOMPLISHED AND FRIENDSHIPS ARE ENJOYED.

SHELTERED WORKSHOPS HAVE A PURPOSE IN THE CONTINUUM OF SERVICES FOR THOSE WITH INTELLECTUAL DISABILITIES.

CLEARLY, THERE IS A NEED FOR MORE EMPLOYMENT CHOICES, NOT LESS.

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VOR (www.vor.net) – OUR NATIONAL VOICE

VOR continues to be our national voice for our family members.

VOR has sent official requests to the U.S. House Appropriations Committee, subcommittees Labor, Health and Human Services, Education, and Related Agencies and Commerce, Justice, Science, and Related Agencies concerning Bill Language and Report Language for 2017 U. S. Appropriations.

The suggested language is to address the misuse of federal funds promoting forced total deinstitutionalization for persons with intellectual disabilities and to provide protections to individuals choosing intermediate care facilities as their homes. Sadly, many individuals with intellectual disabilities have been forced into a community that is not prepared to meet their needs, often resulting in tragic consequences.

VOR is keeping abreast of guardianship law revisions across the country to ensure the changes protect rights of the ward and the rights of court appointed guardians.

VOR ANNUAL CONFERENCE AND CONGRESSIONAL VISITS

The VOR 2016 Annual Conference and Washington Initiative will be held June 4-8, 2016 in Washington, D.C. The focus of the 2016 conference is “VOICES FOR CHOICE”.

The conference is a valuable way for families across the United States to meet each other and develop ways to support each other in advocating for a full continuum of care for persons with intellectual disabilities.

The annual Congressional visits are vital to continue to educate U.S. senators and representatives about the importance of a full continuum of services for persons diagnosed with an intellectual disability.

PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2016

Dues are \$5.00 a year. Make checks payable to "Belleville Habilitation 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**

VOR is your national voice.

Help our voice be strong for people with intellectual and developmental disabilities.

VOR (vor.net)

To join or contribute:

\$40 per year per individual;

\$200 per year per family organization; or

\$250 per year per provider/professional organization

Thank you for joining or renewing!

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Gifts to VOR are tax-deductible to the fullest extent of the law, as no goods or services are provided in consideration of a gift.

Online form: www.vor.net

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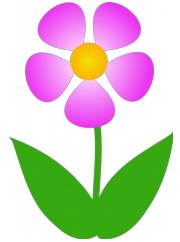
**THE HIDDEN TREASURE SHOP
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BLDG #1901 FIRST BUILDING ON THE LEFT AS YOU ENTER BHC CAMPUS.

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.
BELLEFONTAINE HABILITATION CENTER
10695 BELLEFONTAINE ROAD
ST. LOUIS MO 63137

FORWARDING AND ADDRESS
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