

**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



NEWSLETTER AUGUST 2021

PARENTS ASSOCIATION MEETING

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.

THE AUGUST PARENTS ASSOCIATION MEETING HAS BEEN CANCELLED

PENDING 2021 PARENT ASSOCIATION MEETING DATES
MARK YOUR CALENDARS!!

NOVEMBER 14

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. Pass it along to others.

Wishes for a return to complete health to all who have contracted the virus.

Sincere appreciation to all BHC staff for your dedicated daily work during the COVID pandemic.

Rules for visiting residents may change as virus statistics change.

COVID 19 vaccinations continue be encouraged.

The 2021 Missouri Legislative Session ended on May 15, 2021. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to www.mo.gov.

There continues to be a strong, persistent effort nationwide to close all congregate care facilities like habilitation centers, despite current federal regulations in support of choice based on need such as:

The 1999 Supreme Court Olmstead decision that interprets the 1990 Americans with Disabilities Act states:

"Nothing in the ADA or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." *Olmstead*, at 601 – 602

"It would be unreasonable, it would be a tragic event, then, were the American with Disabilities Act of 1990 (ADA) to be interpreted so that States had some incentive, for fear of litigation, to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." *Olmstead*, at 610.

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>
Jean Brinkmeyer		donation
Jacqueline Kearney		donation
Rosemarie Lacasse		donation
Steve & Mary Vitale	Mickey Slawson	in memory of Carol Slawson

Sincere condolences are expressed for the Slawson family upon the death of Carol Slawson, beloved daughter of board member Mickey Slawson.

The BHC Parents Association expresses our deep sympathy for Department of Mental Health staff and clients who have died from the COVID 19 virus.



FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$ 5700.00 Annual Picnic

THE HIDDEN TREASURE THRIFT SHOP HAS BEEN CLOSED DURING THE PANDEMIC.

LESS FUNDS ARE COMING IN.

NOW WOULD BE A GOOD TIME TO MAKE A DONATION TO

THE BHC PARENTS ASSOCIATION

ANNUAL BHC PICNIC, SEPTEMBER 16, 2021

The picnic will again be scaled back to protect the health of residents and staff.

The theme this year is Dr. Seuss.

The activities will be brought to the homes. There will be no large gatherings.

Staff are working hard to continue this tradition that gives the residents so much joy, but doing it in a safe way. All plans are pending.



At this time, no one but staff and residents will be allowed to be at the picnic, because of COVID 19 restrictions.



BHC RESIDENT ACTIVITIES, SPRING AND SUMMER

Valentine and Easter were celebrated with parties in each home. Each resident received a bag of snacks according to their dietary level. Residents enjoyed the Valentine and Easter activities brought to each home during the week of the holiday including holiday DVDs to watch during their parties.

Programming activities were sent to the homes before resuming normal programming.

Morning programming resumed in May. Each home has their own program area and each person has their own programming materials.



The pool has reopened in May. Residents are happy to be able to use the pool - with limited attendance. The schedule was revised to only accommodate people from one home at a time.

A few residents were able to go fishing at the Bellefontaine Conservation area. A good time was had by all who attended.



Having meaningful activities during the day is important for the daily welfare of BHC residents.

Thanks to staff for creating programs during the COVID 19 restrictions.

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WEBSITES FOR INFORMATION

An information and education webinar is hosted by the Division of Developmental Disabilities monthly. Previous webinars are posted.
<https://dmh.mo.gov/dev-disabilities/webinar>

Positive COVID 19 Cases for the Department of Mental Health can be tracked at the following website.
<https://dmh.mo.gov/disaster-services/covid-19-information/dmh-positive-cases-data>

Department of Mental Health/Developmental Disabilities
<https://dmh.mo.gov/dev-disabilities>



Department of Health and Senior Services
<https://health.mo.gov/>

Show Me Hope Crisis Counseling Program
<https://www.moshowmehope.org/>

Show Me Hope is Missouri's Crisis Counseling Program in response to the COVID-19.

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DIVISION OF DEVELOPMENTAL DISABILITIES RESIDENTIAL WAIT LIST

<https://dmh.mo.gov/media/pdf/residential-wait-list>

In Missouri, 79 families looking for residential placement are on the wait list for services. In violation of federal law these families will not have the opportunity to have the choice of a habilitation center because of the closed admissions policy of the Department of Mental Health. If these families lived in the neighboring states of Illinois or Arkansas, they would have the choice of homes like habilitation centers as provided by federal law.

The Code of Federal Regulations, C.F.R. § 441.302(d) states:

“d) Alternatives - Assurance that when a beneficiary is determined to be likely to require the level of care provided in a hospital, NF, or ICF/IID, the beneficiary 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.**”

NEW DEVELOPMENTAL DISABILITIES DIVISION DIRECTOR NAMED

“The Department of Mental Health (DMH) is pleased to announce Jessica Bax as the new Director of its Division of Developmental Disabilities (DD), effective May 10, 2021.

Ms. Bax joins the DMH team with more than 16 years of experience in state government at the Department of Health and Senior Services. She began her tenure in 2005 working in the Division of Senior and Disability Services. She served in various roles in the Division Director’s office including Constituent and Emergency Services Manager and Bureau Chief of Medicaid Long Term Services and Supports. Ms. Bax worked her way into leadership roles becoming the Deputy Director and then ultimately the Division Director in 2018.

Ms. Bax has extensive experience and knowledge of Medicaid and social service programs as well as the budget and legislative process. She works collaboratively with state and local agencies and successfully built partnerships with stakeholders. Ms. Bax has excellent networking and research connections to identify national best practices.

Ms. Bax has a Bachelor of Science degree in education from Lincoln University and a master’s degree in Public Affairs from the Harry S Truman School of Public Affairs at the University of Missouri -Columbia.

Ms. Bax is replacing Valerie Huhn who was named Deputy Director of DMH in October 2020.”

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2022 MISSOURI BUDGET

Governor Mike Parson signed Fiscal Year 2022 state operating budget bills on Wednesday, June 30. The Missouri FY22 state budget is approximately \$35.6 billion.

The 2022 FY budget for Missouri will have a record budget surplus - \$1.2 billion.

The huge surplus is due to federal COVID 19 pandemic aid and to tax revenues collection delayed from FY2020 to FY2021.

Adding to the current surplus, more federal funding will be available to states through U.S. Congressional action such as the American Rescue Plan, signed on March 11, 2021.

Appropriations for the Department of Mental Health can be found in House Bill 10 at:

<https://www.house.mo.gov/billtracking/bills211/hlrbillspdf/0010H.06T.pdf>

A complete list of FY2022 appropriations are listed at:

<https://oa.mo.gov/budget-planning/budget-information/2022-budget-information/appropriation-bills-fy-2022>

With a generous surplus in the Missouri budget, now would be an opportune time to fund capital improvements of maintenance and repair at the Bellefontaine Habilitation Center.

Because the campus is home where persons with multiple disabilities live, and where the staff who care for them work, the condition of the roads and parking lots should be a highest priority use of funds.

A complete renovation of the roads and parking lots is a critical need of most importance so that residents, staff, and visitors can safely move around the campus.

Contact your state legislator to let them know of this critical capital improvement need.

To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to www.mo.gov.

The article below is printed in full as it expresses the experiences of many families as they search for the best care for their family member with severe intellectual disabilities. It highlights dangerous policies that would eliminate any form of congregate care like habilitation centers in Missouri.

“When It Comes to People Like My Daughter, One Size Does Not Fit All”

Opinion | For People With Disabilities, One Size Does Not Fit All - The New York Times (nytimes.com)

July 4, 2021

By David Axelrod Mr. Axelrod was the senior strategist for Barack Obama’s 2008 campaign. His daughter Lauren lives in Misericordia on Chicago’s North Side

My daughter, Lauren, turned 40 last month. She is happy and healthy. And that is nothing short of a miracle.

From the moment my wife, Susan, found Lauren blue and limp in her crib at the age of 7 months — the consequence, we later would learn, of epileptic seizures she suffered in the night — Lauren’s life has been a struggle.

These brutal seizures would continue, poorly controlled, for the next 19 years, roiling her developing brain and necessitating an ever-shifting regimen of medications with punishing side-effects, of surgeries and hospitalizations. More than once, we feared we would lose her. Lauren’s doctors finally found a cocktail of medications that would work to subdue the seizures, but the battering her brain took from the ordeal left her with significant developmental deficits.

We moved our family from one town to another in search of special education programs that would include her, with adaptations, in regular classrooms. But as the years went by and her classmates matured emotionally and intellectually, the gap between Lauren and her peers became a chasm. The girls and boys around her were growing into young women and men, with all that entails, while Lauren was still in many ways a child, poignantly struggling to find her place.

Lauren’s seizures had been terrifying and painful. But her loneliness was absolutely heartbreaking. She longed for friendships and, whenever she got the chance, gravitated to others with similar challenges and shared experiences. Lauren didn’t need words, which were often hard for her to find, to communicate loud and clear to us what mattered most to her.

When high school ended, we faced a cliff familiar to many parents of children like Lauren. In Illinois, as in most states, jobs and services for adults with disabilities are woefully inadequate. We struggled to find programs and opportunities for the relationships that Lauren craved.

We agonized over whether this would be her future, sitting at home, waiting for activities, without an independent life of her own. We anguished over what would happen when we were gone.

But 19 years ago, that all changed.

Lauren moved to Misericordia, a remarkable community for people with intellectual disabilities near us on Chicago’s North Side. For the first time, her days were rife with activities and her life was filled with friends.

No, it’s not the life we envisioned for Lauren the day she was born, a seemingly healthy, bright-eyed little girl. But looking back at the obstacles she’s faced, she’s thriving in ways that once seemed impossible.

Lauren shares an apartment with two other women in a bustling dormlike setting on a pleasant, leafy campus. She and her friends walk to nearby shops and restaurants. She has vocational activities and jobs on campus and off, which have given her a sense of worth and responsibility. She sings and signs in a choir, takes art and cooking classes, and hits the fitness center or pool every day.

While she has the care and supervision she continues to need — and always will — she also is more independent than we ever could have hoped.

Most of all, she is happy. Genuinely happy.

I wish that were the end of the story.

But today, Lauren faces another battle, not with epilepsy or the toll it’s taken, but with policy changes that could deny her and others with intellectual disabilities the life they choose in concert with their families and loved ones.

The issue is federal Medicaid funding to states, which helps underwrite residential facilities for people with intellectual disabilities, and the conviction of some advocates and policymakers that larger settings like Misericordia should be discouraged.

The debate is rooted in an ugly history. For generations, Americans with intellectual disabilities were too often sent to large institutions where they were warehoused, abused and deprived of the opportunity to live their fullest possible lives.

I am profoundly grateful for the disability rights movement that has waged a decades-long battle to shutter such institutions, many of which were run by the states, and to win for people with intellectual disabilities the right to live in small apartments and homes with services in residential neighborhoods.

But now the ideal has hardened into dogma: All larger communities are bad. All small, neighborhood-based group homes are good.

Of course, neither of these things is true, and the rigidity of that thinking denies the simple truths that there are good and bad places, large and small, and people with disabilities are not all the same. Like anyone else, they have different personalities, capacities and preferences.

Some may thrive in small homes or apartments in residential neighborhoods. Lauren has that option through Misericordia but prefers the socialization of her dormlike setting and the constant stimulation of campus life.

But rather than ensuring a full range of high-quality residential options for people with disabilities to fit their individual needs and circumstances, the prevailing view of many policymakers is to compel a one-size-fits-all answer.

What is painful is that these changes are being promoted by good people, trying to do the right thing. Many are my friends and former colleagues.

We saw this play out through the American Rescue Plan Act, enacted in March, which explicitly provided disproportionate aid to smaller community-based group homes and in-home care settings over larger settings like Lauren's home in Misericordia.

The Rescue Act included emergency funding to increase pay for direct-care workers in home and neighborhood-based settings. But it omitted equally deserving women and men who work in larger settings and devotedly support Lauren and others. (Misericordia received some of this emergency funding but only for its neighborhood-based group homes, not the main campus.)

Now a proposal by Democratic leaders in Congress — the Better Care Better Jobs Act — would vastly expand federal funding for home and community-based services for the elderly and people with disabilities, which I strongly support. It is badly needed and long overdue.

But as currently written, the plan also would make the funding disparity based on size and type of care permanent, which is wrong. It is a formula that disadvantages larger settings and gives states further incentive to shift away from them, even if they are doing extraordinary work.

Instead of judging by size, isn't the right path to fully fund an array of high-quality options and afford people like Lauren the dignity of choice and the happiness they deserve?

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2021 VOR ANNUAL CONFERENCE AND CONGRESSIONAL VISITS

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

The 2021 VOR Annual Conference with Congressional visits was a virtual event this year. Zoom and conference calls to U.S. Senators and Representatives were held May 17-20. The Annual Conference membership meeting was held on June 27. The Congressional offices expressed how important these meetings are, as they hear from many disability organizations that want to eliminate homes like habilitation centers.

VOR OPPOSES:

H.R.4131 & S.2210 - The Better Care Better Jobs Act - While this bill would greatly increase the amount of federal funding for people with I/DD, it only supports those in waiver programs receiving Home and Community Based Services. It unjustly discriminates against those who have chosen Intermediate Care Facilities as the necessary and proper form of residential treatment. By giving a 10% increase in federal matching funds only to HCBS clients, and providing training and increased pay only to direct support professionals working in HCBS facilities, the act deliberately favors one form of treatment over another, one ideology over another, and one set of people with I/DD over another.

H.R. 603 & S. 53 - The Raise the Wage Act - These bills are aimed at raising the minimum wage, but they also have provisions to phase out and ultimately eliminate vocational centers and 14 (c) wage certificates over the next six years and to immediately stop the issuing of any new certificates. VOR believes the issue of employment options for individuals with intellectual disabilities should not be buried in a bill for raising the federal minimum wage. Both issues deserve clean, stand-alone bills.

H.R.1880 - To amend the Deficit Reduction Act of 2005 to make permanent the **Money Follows the Person (MFP) Rebalancing Demonstration**. MFP should not be reauthorized on a permanent basis.

H.R. 2383 - The Transformation to Competitive Integrated Employment Act - this bill purports to assist employers providing employment under special certificates issued under section 14(c) of the Fair Labor Standards Act of 1938 in transforming their business and program models to models that support individuals with disabilities through competitive integrated employment, to phase out the use of such special certificates. We feel that, if enacted, tens of thousands of people with I/DD and autism will still be forced out of opportunities they currently, needlessly, and left without viable alternatives to occupy their time or address their needs and their abilities.

VOR SUPPORTS:

VOR takes no position on whether or not the minimum wage should be raised to \$15 per hour, or some other amount. We do, however, **oppose** any bills (see H.R. 603 & S. 53, above) that would remove vocational centers and 14(c) wage certificates.

For those who do support raising the minimum wage, there are currently two "clean" bills in the House that would raise the minimum wage without taking opportunities to work in a therapeutic environment through the use of 14(c) certificates. Those bills are **H.R. 112**, from Rep. Al Green (D-TX) and **H.R. 325**, from Rep. Steve Cohen (D-TN)

Additionally, Senator Tom Cotton (R-AR) has introduced a bill in the Senate, **S 478**, that would raise the minimum wage to \$10 over a period of three years for some workers, without eliminating 14(c) wage certificates. The bill would also require the Department of Homeland Security to implement electronic verification to verify that prospective employees are legally authorized to work in the U.S.

Call your representative and senators. Let them know about your opinions. Leave a message if they are not available when you call.

The U.S. Capitol switchboard number is (202) 224-3121. You can ask to be transferred to their offices. You may also go to their web pages and contact them.

IN MEMORY OF _____

ON THE OCCASION OF _____

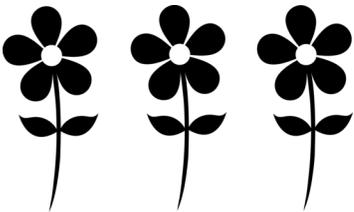
PLEASE SEND TO (name) _____

(address) _____

FROM (name) _____

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
BEST THRIFT SHOP PRICES!!**

CLOSED AT THIS TIME!!!

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

FORWARDING AND ADDRESS
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