

**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 2020

**THE AUGUST PARENTS ASSOCIATION MEETING HAS BEEN
CANCELLED**

2020 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!

NOVEMBER 8 – PENDING



HEROES WORK HERE!

HEROES WORK HERE!

HEROES WORK HERE!

There are not enough words to express our deep appreciation and gratitude to all BHC staff for their daily commitment to residents at BHC during this COVID-19 pandemic crisis. Your dedication is:

Commendable

Exceptional

Exemplary

Extraordinary

Impressive

Outstanding

Remarkable

Superior

Special thanks to the “Sweatshop Crew” for their mask sewing expertise.

The Parents Association expressed thanks to BHC staff with small QT gift card

Restrictions on family visits is a great hardship for families. Plans are being considered, with the health of the residents of the utmost importance.

An information and education webinar concerning COVID 19 is hosted by the Division of Developmental Disabilities on Fridays. <https://dmh.mo.gov/dev-disabilities/webinar>

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 friends, family, and political leaders.

Wash your hands, social distance 6 feet, wear a mask.

Keep informed. Take action. Mary A. Vitale, President, Bellefontaine Parents Association
AUGUST 2020 PAGE 2

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>
Frederick Brueggemann		donation
Jeanette Craig		donation
William and Laurie Donovan		donation
Nancy Hartman		donation
Jacqueline Kearney		donation
Lyn McQueary		donation
Norma Vance		donation
Colleen Jones	Norma Lingle family	in memory of Norma Lingle
Steve and Mary Vitale	Norma Lingle family	in memory of Norma Lingle
Sandra Weihe	Norma Lingle family	in memory of Norma Lingle

We express our sincere sympathy to the family of Norma Lingle. Norma passed away on March 5, 2020. Norma's dedication to all of the residents at BHC was seen in her lifelong service to the betterment of their daily life on the BHC campus. This dedication was apparent whether working in the Hidden Treasures Thrift Shop, serving on the Parent Association Board, attending general Parent Association meetings, supporting BHC staff, or participating in the VOR annual conference in Washington, D.C. Norma has left an example of faithful commitment to make BHC a safe, healthy, happy home for residents. We will miss her immensely.

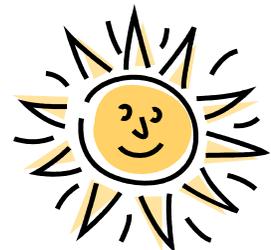
Our deep sympathy also is expressed for the COVID 19 related deaths of any consumer being served by the Department of Mental Health and of any staff member serving them. We share the sorrow of the families affected by these sad deaths.



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FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

- \$ 325.00 Valentine treats, decorations for dance in gym
- \$ 325.00 Easter treats, decorations for dance in gym
- \$ 1375.00 Birthday Gifts, July-Dec
- \$ 1758.00 Personalized Birthday Cakes, 2020/2021
- \$ 5138.00 Annual Picnic, scaled back, plans pending



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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The Parents Association extends a note of thanks for a generous donation from the Knights of Columbus, Fr. Griffin Council No. 3586. These are proceeds from the 2019 Annual Tootsie Roll Drive.



ANNUAL BHC PICNIC, SEPTEMBER 17, 2020



The theme this year is Superheroes.

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

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.

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BHC RESIDENT ACTIVITIES BEFORE & AFTER COVID 19

Before the COVID 19 restrictions, some shopping trips included Walmart, Dollar Tree, Schnucks, and Big Lots.



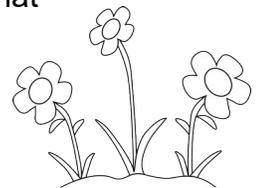
Residents enjoyed eating out at Rice house, Golden Corral, Dairy Queen, Panda Express, and Taco Bell.

Other activities included home visits, a Flea Market, and attending the Florissant Assembly of God Church.

After COVID 19 restrictions, staff continued to engage residents led by the Active Treatment team. Residents have been provided daily activity packages of adult coloring pages, puzzles, word searches, and mazes. Worksheets, Bingo games, and memorabilia conversation cards are used to address Daily Objectives – identifying objects, foods, drinks, colors, shapes, numbers, personal hygiene and chores.

Residents have decorated sun catchers, magnets and personalized their own baseball hat

Apt. B has their garden planted. It is growing like wild fire. Another garden is planted behind the pet room for anyone that loves veggies. All the flowers have been planted at the homes.



EXCEPTIONAL CARE DURING THE COVID 19 PANDEMIC

Led by the Division of Developmental Disabilities, and carried out by facility staff members, the care given to residents living in Missouri intermediate care facilities for individuals with an intellectual disability (ICFs/IID) (habilitation centers) during this historic COVID-19 pandemic is highly commendable. Ongoing steps being taken to protect residents and staff from the COVID-19 virus include:

- coordinating with national, state, and local health officials to take all necessary precautions to prevent the spread of the virus
- deciding early to stop visitation
- having residents remain on campus unless for an emergency
- screening of staff for fever and other symptoms
- frequent monitoring of symptoms for all residents
- limiting movement of staff and residents on facility grounds
- providing personal protection equipment for staff
- hiring a cleaning company to provide extra sanitation
- giving quick notice of positive test results for staff and residents
- staff members testing positive remain at home
- isolating residents who tested positive for the virus
- testing of all BHC staff and residents, with continued surveillance testing



NO FAMILY VISITATION, GUIDELINES FOR PLANS, WATCH FOR UPDATES

<https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/visitation-guidance.pdf>

As of this writing, the Missouri Departments of Health and Senior Services has issued the following guidelines when considering visitation at all long term care facilities, including habilitation centers.

TO: All Long-Term Care Facilities

FROM: Director Randall Williams, MD, FACOG

DATE: June 15, 2020 RE: COVID-19 Visit Guidance Considerations for Long Term Care Facility Visits

The Missouri Department of Health and Senior Services (DHSS) is dedicated to protecting the health and safety of our citizens. This especially includes those Missourians that make their home in residential care facilities, assisted living facilities, intermediate care facilities, skilled nursing facilities, and intermediate care facilities for individuals with intellectual disabilities.

Each facility will make the final decision to allow visits. The below guidance is for facilities wanting to allow outdoor visits and visits through an open window for residents who are bedbound or who cannot otherwise leave their room.

Facilities may want to consider the following when allowing visits:

- The facility has not had any COVID-19 staff or resident cases, or it has been two incubation periods (28 days total) since the last facility acquired COVID-19 positive case. Facility acquired cases include all staff who test positive and residents who test positive while residing in the facility.
- Limiting outdoor visits to only residents who are;
- COVID-19 negative or asymptomatic and not suspected to have COVID-19 OR
- Previously COVID-19 positive but have been released from isolation based on either the symptom based or test based strategy.
 - Allowing up to two visitors at one time with social distancing (spaced by at least 6 feet), hand hygiene before and after each visit for both the resident and the visitors, and use of a cloth face covering or facemask for both the resident and the visitors. In the event a resident cannot safely wear a cloth face covering or facemask, a plastic partition or plexiglass barrier may be considered to prevent the spread of virus.
- Completing a screening upon arrival of each visitor and allowing only those visitors that meet the screening criteria to visit. Components of the screening are to determine whether the visitor has ever been diagnosed with COVID-19 and if so, the visitor should be currently asymptomatic and at least 10 days must have passed since disease onset. Facilities may want to consider not allowing any visitor with signs and symptoms consistent with COVID-19 or who are unable to demonstrate proper use of infection control techniques to visit.
- Keeping visitor logs noting the names of visitors, who they visited, staff that assisted the visit, dates of visit, and contact information in the event of subsequent positive COVID-19 cases among staff or residents.
- Sanitizing any outdoor areas, including tables, chairs and partitions between each and every visit using an EPA approved disinfectant in accordance with instructions for dilution and contact times.

MISSOURI 2020 LEGISLATIVE UPDATE

The 2020 Missouri Legislative Session ended on May 15, 2020.



Appropriations for habilitation centers remains stable, despite cuts to the Missouri budget due the COVID 19 virus. Budget and appropriation information in House Bill 2010, and Governor Parson's letter of restrictions can be found at:

<https://www.house.mo.gov/Bill.aspx?bill=HB2010&year=2020&code=R>

All 163 House seats and half of the 34 Senate seats are up for election in November this year, as well as the 5 state executive offices: Governor, Lieutenant Governor, Attorney General, Secretary of State and Treasurer.

Get to know your legislators. Invite them to visit a habilitation center. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to www.mo.gov.

MISSOURI RECEIVED CARES ACT FUNDING

<https://treasurer.mo.gov/COVID>

<https://treasurer.mo.gov/pdfnew/Supplemental.pdf>

<https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/cares-act-funding.php>



The Coronavirus Aid, Relief, and Economic Security (CARES) Act was passed by Congress and signed into law by President Trump on March 27th, 2020. The CARES Act established the \$150 billion Coronavirus Relief Fund.

Treasury has made payments from the Fund to States and eligible units of local government. The CARES Act requires that the payments from the Coronavirus Relief Fund only be used to cover expenses that—

1. are necessary expenditures incurred due to the public health emergency with respect to the Coronavirus Disease 2019 (COVID–19);
2. were not accounted for in the budget most recently approved as of March 27, 2020 (the date of enactment of the CARES Act) for the State or government; and
3. were incurred during the period that begins on March 1, 2020, and ends on December 30, 2020.

Missouri Total Coronavirus Relief Fund Allocation: \$2,379,853,017

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WEBSITES TO KEEP UPDATED ON COVID 19

Department of Mental Health
<https://dmh.mo.gov/>

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

Division of Developmental Disabilities COVID-19 Updates and Question/Answer SESSION
<https://dmh.mo.gov/dev-disabilities/webinar>

Department of Mental Health/Developmental Disabilities/COVID 19
<https://dmh.mo.gov/dev-disabilities/covid-19-information>

State Operated Homes and COVID 19 Cases Statistics
<https://dmh.mo.gov/disaster-services/covid-19-information/dmh-positive-cases-data>

Department of Health and Senior Services
<https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/>

Guidelines for Long Term Care Facilities Family Visits <https://health.mo.gov/living/healthcondiseases/communicable/novel-coronavirus/pdf/visitation-guidance.pdf>

U.S. Center for Disease Control
<https://www.cdc.gov/coronavirus/2019-ncov/index.html>



ATTACKS ON ALL CONGREGATE CARE SETTINGS, INCLUDING HABILITATION CENTERS

Headlines have covered the devastating death rate in long term care facilities from the COVID 19 virus, many coming from nursing homes. From the very onset of reports of these too high death rates, there have been many articles written attacking any and all types of congregate care, including homes like habilitation centers.

As can be seen by the success of the BHC staff to minimize resident and staff virus cases, living in a congregate care setting does not have to mean a high death rate.

One major effort to lump all congregate care together and call for closure is a petition by the Americans for Civil Liberties Union (ACLU).



The national organization, VOR, (vor.net) sent the response below.

VOR Response to ACLU/SEIU Call for Cuts to Congregate Care

<https://vor.net/legislative-voice/advocacy-letters/item/vor-response-to-aclu-seiu-call-for-cuts-to-congregate-care>

In a petition dated June 23, 2020 filed with the U.S. Department of Health and Human Services (HHS), the ACLU, SEIU, and several partner groups outlined concerns with the federal response to the novel coronavirus epidemic and used these concerns to call for a 50 percent reduction in congregate care nationwide. The petitioners defined congregate care to include nursing homes, intermediate care facilities for individuals with intellectual disabilities (ICFs/IID), psychiatric facilities, and home and community-based services (HCBS) group homes.

On July 1st, VOR issued a firm response in opposition to ACLU and SEIU's irresponsible and unreasonable demand which would remove all forms of long-term care for the elderly and persons with mental disabilities, except for the family home or private residence.

In response to the ACLU's petition, VOR wrote:

"...the ACLU has cast its net too wide, and falsely claimed to represent the interests of everyone receiving federally funded services who is classified as elderly or who has intellectual and developmental disabilities. In doing so, it apparently assumes that all such persons look and feel alike and need the same supports and level of care. We, who represent our family members and loved ones with I/DD, must disagree with that assumption that ignores the diversity and the very rights of this vulnerable population. We, therefore, must soundly reject the petitioner's claim to represent us."

For the complete response go to:

<https://vor.net/legislative-voice/advocacy-letters/item/vor-response-to-aclu-seiu-call-for-cuts-to-congregate-care>

VOR ADVOCACY NOTES: U.S. CONGRESSIONAL BILLS

www.vor.net

VOR OPPOSES:

[H.R. 555 & S. 117 - The Disability Integration Act](#) - This bill has written into it the goal of eliminating "institutional care". In addition to the inherent bias against ICF's and people with severe and profound I/DD, the bill is prohibitively costly and there are not enough Direct Support Professionals to meet the provisions of this act.

[H.R. 582 & S. 150 - The Raise the Wage Act](#) - This bill is aimed at raising the minimum wage, but it also has provisions to eliminate 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. 873 & S. 260 - The Transformation To Competitive Employment Act](#) - This bill has declared the goal of eliminating Sheltered Workshops and 14(c) Wage Certificates, under the mantle of everyone with a disability is capable of competitive integrated employment.

Sponsors of the bill recently added a new summary that significantly downplays the effect the bill would have on eliminating work centers and 14(c) that benefit those who are unable to compete in the employment opportunities the bill promotes.

VOR SUPPORTS:

[H.R. 6045 & S. 3669 - Recognizing the Role of Direct Support Professionals Act](#) - To require the Office of Management and Budget to revise the Standard Occupational Classification system to establish a separate code for direct support professionals, and for other purposes.

[H.R. 5443 & S. 3220 - Ensuring Access to Direct Support Professionals Act](#) -

To amend title XIX of the Social Security Act to clarify that the provision of home and community-based services is not prohibited in an acute care hospital, and for other purposes.

[H.R. 2417 - The HEADs UP Act](#) - To amend the Public Health Service Act to expand and improve health care services by health centers and the National Health Service Corps for individuals with a developmental disability as a Medically Underserved Population (MUP).

[H.R. 1379 & S. 560 - Ensuring Lasting Smiles Act](#) - To require that group and individual health insurance coverage and group health plans provide coverage for treatment of a congenital anomaly or birth defect. (i.e. Cleft palate, ectodermal dysplasia, etc.)

“ONE SIZE DOES NOT FIT ALL” FOR CARE FOR PERSONS WITH AUTISM

[phttps://www.psychologytoday.com/us/blog/inspectrum/202006/when-autism-advocacy-is-partial?fbclid=IwAR2TDaeDofoil-HcQQAJGoiaWzzbrVjXof22Gccn3qxNA0WQ-Tc0D3pHsiU](https://www.psychologytoday.com/us/blog/inspectrum/202006/when-autism-advocacy-is-partial?fbclid=IwAR2TDaeDofoil-HcQQAJGoiaWzzbrVjXof22Gccn3qxNA0WQ-Tc0D3pHsiU)

This article emphasizes that the idea of one size fits all needs of all persons with intellectual disabilities “can misinform policymakers and the public about the interests of represented groups, leading, in turn, to suboptimal or harmful policies”.

When Autism Advocacy Is "Partial"

A new concept emphasizes the need for transparency in representation claims.

Posted Jun 23, 2020

By Amy Lutz

It may seem like there are many different issues splitting the autism community—including fights over educational, vocational, residential, medical, and therapeutic services. But these battles really boil down to just one question: Who decides what’s best for those who can’t speak for themselves, the severely autistic individuals who will require upwards of \$2.4 million in care over the course of a lifetime? Should it be parents or should it be autistic self-advocates?

For the past four years, I’ve been privileged to work with three Penn colleagues, Matthew McCoy, Emily Liu, and Dominic Sisti, mining literature in bioethics, political philosophy, and history for guidance in crafting a framework that would be helpful in analyzing these debates. In March, our article “Ethical Advocacy Across the Autism Spectrum” was published in *The American Journal of Bioethics*. In the article, we suggest a new concept, “partial representation” to describe advocacy that is both incomplete and biased—in other words, “when an actor claims to represent a particular group of people, but appropriately engages with only a subset of that group.”

One of our primary examples of partial representation is the Autistic Self Advocacy Network (ASAN), which claims to speak for all autistic people. ASAN has taken several positions—including opposing the use of tracking devices to prevent elopement and supporting the restriction of Medicaid HCBS funding to residential settings no larger than four people—that many parents consider not in the best interests of their severely autistic children and potentially harmful to them. Some self-advocates, in response, have pointed to their shared diagnosis to assert a right to determine the best interests of autistic individuals—including of much more impaired autistic individuals they have never met.

In our paper, we argue that any group that purports to represent the entire autism community is obligated to “actively engage and consult with both autistic people and those closest to autistic people who lack the capacity to participate in decision making themselves.” Admittedly, this is easier said than done.

We also use the example of Autism Speaks, which ASAN has accused of taking the same representative role it claims for itself and speaking for the entire autism community without, on the flip side, inviting the participation of self-advocates. In response to these criticisms, Autism Speaks has tried to broaden its constituency, by adding autistic adults to its board and removing the word “cure” from its mission statement in 2016. But this has done little to appease some self-advocates while alienating some of the parents who were the group’s core supporters.

In my opinion, autism has just become too broad—representing both married college graduates and profoundly intellectually disabled adults who spend their lives in diapers and helmets (to prevent traumatic brain injury from smashing their heads against the wall)—to be fairly represented by one voice.

Which isn’t necessarily a bad thing. As we note in the paper, there may be another solution to partial advocacy besides including all stakeholders: the “moderating [of] representative claims and making it clear that [a group] represents only that constituency with which it is appropriately engaged.” The Global and Regional Asperger Syndrome Partnership (GRASP), for example, has supported individuals with milder forms of autism since 2003.

More recently, The National Council on Severe Autism (NCSA), of which I’m a founding board member, launched in 2019 to represent the other end of the spectrum. Neither group claims to speak for the entire autism community. In our paper, we call this “a federated model of representation where representatives of particular subgroups speak on behalf of their smaller constituency when addressing certain issues but come together with other representatives... to speak as one about issues affecting a broader group of people.”

The problem arises when representatives fail to recognize or acknowledge their own partiality. In the paper, we note some real harms that can result: such partial representatives “can ‘crowd out’ other representatives that might do a better job of adequately representing the groups in question,” either in formal settings, like advisory boards, or informally, “when certain representatives dominate public discourse about the needs of a particular group.” In an era when autism has come to be equated with the “quirky genius” of Sheldon in *The Big Bang Theory* and Shaun in *The Good Doctor*, I would argue that this has already occurred.

More importantly, partial representation “can misinform policymakers and the public about the interests of represented groups, leading, in turn, to suboptimal or harmful policies.” This, too, has already happened. ASAN is just one of the Disability Rights organizations that has argued that everyone with an intellectual and/or developmental disability is capable of achieving competitive, minimum-wage employment and living in his or her own apartment. Many states—like Pennsylvania, my state—have tailored their policies accordingly, de-funding the specialized settings required by my son and thousands of other individuals with significant cognitive impairments and dangerous behaviors.

My own takeaway from working on this project? That claims of representation need to be made carefully, with humility and respect for diverse perspectives. And the broader the claim, the more skeptically it should be treated. The fact that the “autism wars” have been raging for two decades over this very question is itself more than enough proof that any claim to speak for every stakeholder is, inevitably, partial.

Amy S.F. Lutz is the author of *Each Day I Like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children*, and is the president of the EASI Foundation.

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 BEST THRIFT SHOP PRICES

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

CLOSED AT THIS TIME!!!



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

**FORWARDING AND ADDRESS
CORRECTION REQUESTED**