

**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 2019

**PARENTS ASSOCIATION MEETING
SUNDAY, AUGUST 11, 2019 2:00 p.m.
Administration Bldg. Room #10**

All Parent Association members, friends and staff are invited. Keep up with the latest news about Bellefontaine Habilitation Center. Bring your talents and expertise for our advocacy efforts. With everyone's involvement, the lives of the residents at BHC will be the best possible. All are encouraged to stay informed and take some action. Attend a parents meeting, talk with other families, share your concerns and ideas, write a letter, or make a phone call to help provide a safe, healthy, and supportive environment for the residents of BHC and others. They have no voice but ours, so we must continually speak up for them. Refreshments served.

UPCOMING PARENT MEETING: AUGUST 11, 2019

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

2019 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!

AUGUST 11 NOVEMBER 10

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.

Thank you to Valerie Huhn, Director of Department of Developmental Disabilities, for the information given at the May 19, 2019 BHC Parent Association meeting. Those in attendance had the opportunity for comments and to ask questions about issues of concern.

Road repair needs continue to be assessed.

The 2018 Missouri Legislative Session began on January 9 and ended on May 17, 2019. Education of all legislators is an ongoing necessity as part of our advocacy for intellectually disabled residents living in habilitation centers. Get to know your legislators. 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.

.In 2019, BHC has provided 95 years of services to persons with intellectual disabilities!! The daily work of all BHC employees is much appreciated,

Attend the upcoming Parent Assn. meeting to help keep habilitation centers good homes for our family members. Your participation is important.

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

Patsy Christen
Richard & Patricia Gill

RECIPIENT

OCCASION

in memory of Patrice Christen
donation



FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

- \$ 200.00 Home 1601, outdoor swing, household goods
- \$ 200.00 Home 1603, outdoor swing
- \$ 200.00 Home 1505, outdoor swing
- \$1400.00 Birthday gifts for each resident, Jul-Dec
- \$1909.00 Birthday cakes for each resident
- \$8500.00 BHC Picnic



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

HEARTFELT THANKS GOES TO KNIGHTS OF COLUMBUS

Much appreciation to the members of the Fr. Griffin Council #3586 of the Knights of Columbus for a generous donation from the annual Tootsie Roll Drive. The funds will go to the benefit of BHC residents.

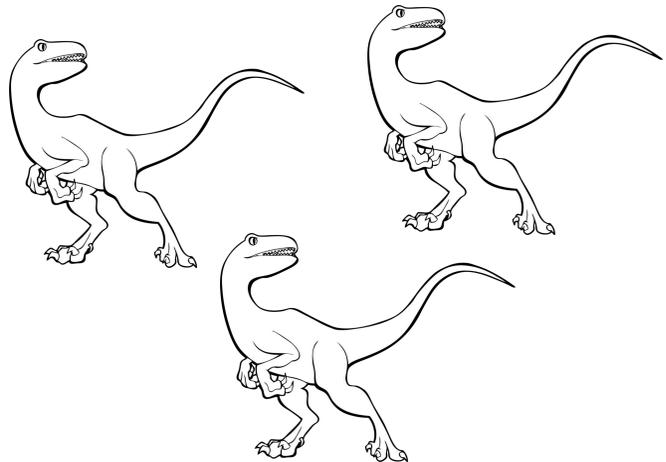
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BHC PICNIC – SEPTEMBER 12, 2019

Theme: Jurassic Park

Date: September 12

Time: 10:30 am Parade
11:00 am Home for lunch
1:00 – 4:00 pm Picnic in the gym



The picnic is limited to parents, guardians, residents and current staff members.

A REMINDER ABOUT MO HEALTH NET AND MANAGED CARE

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

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

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

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

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

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

PARENT ASSOCIATION COMMENTS:

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

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

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UPDATE: MISSOURI SENATE BILL 77-CHANGING MISSOURI MEDICAID PROGRAM TO GLOBAL WAIVER

https://www.senate.mo.gov/19info/BTS_Web/Bill.aspx?SessionType=R&BillID=159



Senate Bill 77 did not pass this legislative session.

It would have made major changes to how MO HealthNet works.

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

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

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

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

Another bill will likely be introduced next year.

PARENT ASSOCIATION COMMENT:

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

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

2019 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 VOR Annual Conference with Congressional visits was held in Washington, D.C. from Saturday, June 8 – Wednesday June 12.

Videos and power point presentations from VOR's 2019 Annual Meeting and Legislative Initiative are available at www.vor.net

The VOR 2019 Conference speakers and presentations were:

Melissa Stone, Director of the Developmental Disability Services Division of the Arkansas Department of Human Services shares her experiences in navigating the Arkansas system and ensuring a full continuum of care to meet all of the needs of the I/DD community.

Video available at www.vor.net

James Edmondson, M.D., PhD As a neurologist and the father of two children with intellectual disabilities, Dr. Edmondson has experienced the LTSS system from two very different perspectives. He has more recently worked in the Medicaid Managed Care sector, and shares his insights and warns attendees about the dangers of states moving Medicaid Long Term Services and Supports for people with I/DD to Managed Care.

Video available at www.vor.net

Amy S. F. Lutz, MA, MFA, author, advocate, and mother of a son with autism, speaks of her personal journey and her work with the EASI Foundation and the National Council for Severe Autism. *Amy is the author of "Each Day I Like It Better". Her articles have appeared in Psychology Today, the Atlantic, Slate, and other publications.*

Video available at www.vor.net

Scheduled meetings with U.S. Senate and Representative Offices were on Monday, Tuesday and Wednesday. At the meetings, VOR conference participants from across the country presented personal family stories and educated about important legislation. Below are the main legislative issues covered:

PLEASE SUPPORT

1. Medicaid Funding for people with Intellectual and Developmental Disabilities (I/DD) without changes that would reduce these critically necessary funds.
2. The HEADsUP Act of 2019. This bill would designate people with I/DD as a Medically Underserved Population, providing them with better funding for primary and specialized care, incentivizing new research, and authorizing more favorable reimbursement rates for providers who treat this population.
3. The Autism CARES Act of 2019, which would extend the Autism CARES Act of 2014 and provide for further research into the causes, diagnosis, and early and ongoing detection, prevention, and treatment of autism spectrum disorder. The bill would also reduce disparities within the autism community by improving access to clinical services for youth and adults from diverse racial, ethnic, geographic and linguistic backgrounds
4. ALL people with Intellectual and Developmental Disabilities by supporting a full range of residential care and employment options.

PLEASE OPPOSE

1. The Disability Integration Act of 2019. This act would eliminate individual or family choice of residential settings for individuals with I/DD, strain federal and state budgets for Medicaid, and overturn key provisions in the landmark 1999 Supreme Court Decision in Olmstead.
2. The Raise the Wage Act and the Transformation to Competitive Employment Act, as long as they contain provisions that would eliminate work opportunities for some individuals with I/DD whose disabilities are so severe they are unable to perform tasks sufficient to warrant the payment of a minimum wage.

<https://vor.net/legislative-voice/legislation/item/2019-legislative-initiative-materials?highlight=WzlwMTk5ImxlZ2ZlbGF0aXZlIiwibWF0ZXJpYWxzIiwiaWJAxOSBsZWdpc2xhdGl2ZSIsImxlZ2ZlbGF0aXZlIiG1hdGVyaWFscyJd>

VOR UPDATES ON FEDERAL LEGISLATIONwww.vor.net**THE DISABILITY INTEGRATION ACT (DIA) SENATE BILL 117, HOUSE BILL 555**<https://www.congress.gov/bill/116th-congress/senate-bill/117><https://www.congress.gov/bill/116th-congress/house-bill/555>

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

The House sponsor is Representative F. James Sensenbrenner, Jr., HR 555.

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

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

As of this writing, there are 234 cosponsors in the House of Representatives, and may go to a committee hearing.

CONTINUE TO TAKE ACTION

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

For a sample letter go to www.vor.net

To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000, or go to: www.mo.gov Look for your federal U.S. senators and representatives.

**PARENT ASSOCIATION COMMENT**

With several years of government reports about lack of quality of care in many waiver community homes, why have a bill to move everyone into these ill prepared homes?

In 2003, the Government Accountability Office report “Long Term Care: Federal Oversight of Growing Medicaid Home and Community-Based Waivers Should Be Strengthened”, found that more than 70 percent of the programs it reviewed had problems with quality of care. <https://www.gao.gov/new.items/d03576.pdf>

In 2012, a report entitled “General Oversight of Quality of Care in Medicaid Home and Community-Based Services Waiver Programs”, 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>

In 2018, a joint report, “Ensuring Beneficiary Health and Safety in Group Homes Through State Implementation of Comprehensive Compliance Oversight”, issued by the U.S. Department of Health and Human Services, Office of Inspector General (OIG); Administration for Community Living (ACL); and Office for Civil Rights (OCR) states “OIG found that health and safety policies and procedures were not being followed. 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>

20TH ANNIVERSARY OF THE SUPREME COURT OLMSTEAD DECISION – MISUSE OF DECISION

The following document from VOR (vor.net) explains how the Olmstead decision of 1999 has been misused to close homes like habilitation centers putting many persons in harm's way.

“VOR acknowledges the 20th Anniversary of the Olmstead Decision and celebrates in its opening doors to community living for people with intellectual and developmental disabilities (I/DD) who are able and wish to take advantage of such opportunities. The Court's decision in Olmstead was balanced and comprehensive. It presented a road map for how to meet the aspirations of those seeking inclusion while protecting the needs of those with more severe intellectual disabilities. VOR is proud of the role that we played in presenting an amicus to the court, showing the need to include all people with I/DD in their ruling.

Recently, the Department of Justice (DOJ), and the Administration for Community Living (ACL) issued press releases celebrating the 20th Anniversary of the Olmstead decision. Unfortunately, their ideological focus with one key part of Olmstead, “community integration”, at the expense of the other key part, “choice”, has reduced options for all people with I/DD and especially those with the most severe and profound forms of I/DD. Whether or not this is an innocent misreading of the ruling or a deliberate misrepresentation of the Court's opinion, this limited interpretation of the plain language of Olmstead has done significant harm to many of our most disabled citizens.

By insisting that all people with I/DD live in the community, the DOJ and ACL are treating people with I/DD as a monolithic group, not as unique individuals. DOJ and ACL are substituting the wishes of the government for that of the person with I/DD or, where relevant, the parent or legal guardian. While their policies have opened doors for the less severely disabled, they have closed important doors for the more severely disabled. Many of these individuals have lifelong needs that require a very high level of care, the kind often found only in public and private Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs/IID).

DOJ and ACL are pursuing this agenda in the name of the ADA and Olmstead, but that is not what the ADA and Olmstead call for. Both the statute and the Supreme Court case embody the best values of American society —nondiscrimination and choice. All of our civil rights laws contain both elements. Civil rights laws do not tell people where they must live or work. They guarantee individuals are not denied opportunities based on a particular factor, and they expand choices for individuals who have suffered discrimination.

In sharp contrast, DOJ and ACL are using federal dollars to bring lawsuits and promote policies that needlessly and dangerously eliminate important options –ICFs/IID, sheltered workshops and facility-based day programs – that many of our most disabled individuals rely on and prefer over small community residences.

In pursuing a one-size-fits-all ideology, DOJ and ACL are ignoring the vital rights of choice embodied in the ADA itself: As the Court clearly stated in Olmstead:

“We emphasize that 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 v. L.C.*, 527 U.S. 581, 601-602 (1999).

In fact, the Court specifically incorporated the right of choice in the second prong of its holding: “(b) the transfer from institutional care to a less restrictive setting is not opposed by the affected individual,” *Olmstead*, at 587.

Even DOJ and ACL's concept of what constitutes the most integrated setting contradicts the view of Justice Ginsburg:

“[For some individuals, no placement outside the institution may ever be appropriate. ‘Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times -perhaps in the short run, perhaps in the long run -for the risks and exposure of the less protective environment of community settings;’ for these persons, ‘institutional settings are needed and must remain available.’ . . . Each disabled person is entitled to treatment in the most integrated setting possible for that person –recognizing on a case-by-case basis, that setting may be an institution” *Olmstead*, at 605.

Not only are DOJ and ACL ignoring the plain language of governing law and decision, they are ignoring the harmful effects of their policies. Journalists have time and again documented the high rates of abuse and mortality for our most disabled citizens who have been forced out of congregate care facilities into unprepared communities(1). Federal agencies should stop dictating the lives of the severely disabled, and instead, join hands with the community of individuals with I/DD to ensure that all people with I/DD receive quality services and supports wherever they choose to reside.

The ADA and Olmstead are the beacons for providing more opportunities for people with I/DD, but they do not dictate one-size-fits-all solutions. They are to provide rights and protection for everyone. Individual choice among the widest possible range of quality living and occupational options is what is necessary to realize the goals of the ADA and Olmstead. VOR supports the full reading of Olmstead, making individual choice of services paramount and ensuring a full range of living and work options in order to meet the spectrum of needs of this very diverse population.

1 .Abuse and Neglect Document: <http://www.vor.net/get-help/more-resources/item/abuse-and-neglect-document>

MISSOURI HAS AN OFFICE OF AUTISM SERVICES

<https://dmh.mo.gov/dd/autism/>

The Office of Autism Services was established in 2008 (633.225 RSMo) to provide leadership in program development for children and adults with autism spectrum disorders, to include establishment of program standards and coordination of program capacity. Topics to search on the website include:

- Initiatives
- Education and Training
- Commission on ASD
- Manuals, Publications, and Reports
- Directives and Publications
- Resources
- Other Websites

14TH ANNUAL THOMPSON CENTER AUTISM CONFERENCE

September 25, 2019

Autism Parent Training Workshop

<https://one.bidpal.net/autismparentday/custom/custom2>

The Thompson Center for Autism & Neurodevelopmental Disorders is hosting an Autism parent training workshop in Chesterfield, MO on September 25, 2019. All parents and caregivers of children with Autism are invited to attend. The workshop will provide an opportunity to learn more about raising a child on the Autism spectrum from some of the leading Autism experts in the country.

For more information and to register for the workshop, visit:

<https://one.bidpal.net/autismparentday/custom/custom2> or contact Louis Nevins at the Thompson Center by e-mail at: trainings@missouri.edu or by calling: 573-884-1619.

September 26, September 27, 2019

<https://one.bidpal.net/tcautismconf/welcome>

Join up for the premier autism conference in the Midwest on Sept. 26-27, 2019. Registration is now open! To register, visit: <http://www.bidpal.net/tcautismconf>.

This conference offers incredible learning and training opportunities for professionals of all stripes who work with people with autism, including special educators, behavior analysts, psychologists, pediatricians, nurses and more!

NATIONAL COUNCIL ON SEVERE AUTISM – NEW ORGANIZATION FORMED

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

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

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

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

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

“You have very mildly affected people on one end, who are college graduates, who are married with children,” she says. But on the other end of the spectrum there are “Adults who are in diapers and helmets and arm braces to prevent them from hitting themselves in the face hundreds of times an hour until they detach their own retinas.”

TRIBUTE FUND FORM (please print)

ENCLOSED CONTRIBUTION _____

IN MEMORY OF _____

ON THE OCCASION OF _____

PLEASE SEND TO (name) _____

(address) _____

FROM (name) _____

(address) _____

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

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



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



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

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

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

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

FORWARDING AND ADDRESS
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