

**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 2017

PARENTS ASSOCIATION MEETING

SUNDAY, MAY 21, 2017 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 21, 2017

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

2017 PARENT ASSOCIATION MEETING DATES: MARK YOUR CALENDARS!!

MAY 21

AUGUST 13

NOVEMBER 12

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.

Worry and confusion was the reaction of families of residents of South County and St. Charles habilitation centers upon receiving phone calls and then a letter announcing the merging of the two centers. Families were not given any forewarning of these changes. They have many questions as to why these plans seemed to arise so suddenly, and what it is going to mean for the daily lives of the residents.

Guardians of residents of the Bellefontaine Habilitation Center (BHC) later received a letter announcing these changes and that some of these residents would be moving to BHC. Because of the possibility of more residents, there are plans to update the group homes on the campus.

These changes seem to be a part of cuts to balance the Missouri budget, as noted in the BHC letter: "based on budget actions taken in the House of Representatives and concurred by the Senate Appropriations Committee."

Balancing the budget should not come at the expense of the safety, health and support of severely disabled persons. All families of these habilitation centers are looking for more information concerning these major changes. There are few details available at this time. Be alert to any new guidance on these plans.

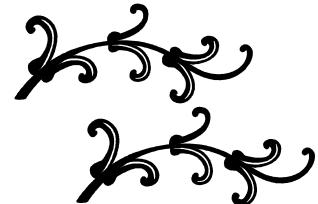
The 2017 Missouri Legislative Session began on January 4 and ends on May 12, 2017. To find your legislators, call the Missouri Capitol Switchboard at 1-573-751-2000 or go to www.mo.gov.

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>
Jeanette Craig		donation
Laurie Donovan		donation
Glen Kaiser		donation
Lee & Jackie Kearney		donation
Lyn McQueary		donation
Theodis Brown		in memory of Ray Hodges
Roseanne Dickey	Creason Family	in memory of Patrick Creason
Roseanne Dickey	Wally Gerards	in memory of Joan Gerards
Roseanne Dickey	Warnake Family	in memory of Martha Warnake
Roseanne Dickey	Mr. & Mrs. Rufbahr	in memory of Gladys Machens
Natale Lucido		in memory of Angela & Earl Radley



Thanks to all who send in tributes in support of activities for BHC residents.

Sympathy goes to the family of John Schneider, Missouri Senator from 1969 to 2002, upon his death in March 2017. He was a strong supportive voice in the Missouri Legislature for the residents of the Bellefontaine Habilitation Center during his many years as Missouri Senator. Because of his devotion to advocacy for the residents, many positive changes were made possible on the BHC campus.

FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$ 300.00 Valentine treats
 \$ 300.00 Easter treats
 \$ 300.00 Household goods, Home 1504
 \$ 300.00 Household goods, Home 1505

**HIDDEN TREASURE THRIFT SHOP**

For over 50 years a multitude of volunteers, spearheaded by Betty Coll, have dedicated endless hours preparing donations for the Wednesday sale days. Thousands of dollars have been earned each year by this devoted work. These generous funds have made possible many opportunities for BHC residents.

Much appreciation to all who work at the Hidden Treasure Thrift Shop, and to all who shop there.

Your dollars spent here goes to a wonderful cause!!

PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2017

Have you paid 2017 dues yet? Dues are \$5.00 a year. Make checks payable to "BHC Parents Association".

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

WINTER/SPRING RESIDENT ACTIVITIES

As usual, BHC residents have taken advantage of many activities off campus and on campus during the last few months.

Activities on campus:



Gym: Movies, basketball, Wii games, volleyball, weekly dances with DJ

Valentine and Easter Dance with cupcakes, pudding, jello, cookies, punch and a DJ

Special Olympics Track & Field events



Off grounds activities:

Billiken Basketball game, Shriner's circus, Bowling, Glass Factory, Museum of Transportation, Parks

Shopping: Walmart, Kmart, Dollar Tree, Mid Rivers Mall, Shop n Save, \$5 below, Petsmart, Michael's Crafts, Target, West County mall, Goodwill, Flea Market, Shoe Carnival, Mills Mall

Out to eat: Culvers, Denny's, La Fuentes, Hibachi Grill, Fazolis, Taco Bell, McDonalds, White Castle, Lee's Chicken, Dairy Queen, Sonic, Burger King, Hometown Buffet, Uncle Bills, and Olive Garden

Staff assistance for so many wonderful opportunities is much appreciated by all.

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MISSOURI ACHIEVING A BETTER LIFE EXPERIENCE (MO ABLE)

In 2015, the Missouri Achieving a Better Life Experience (MO ABLE) was passed into law. Each state had to put regulations in place to participate in the new federal ABLE law that will allow a person who acquired a disability before the age of 26 to open special accounts to save up to \$100,000 without risking eligibility for Social Security and other government programs. Funds accrued in the accounts can be used to pay for education, health care, transportation, housing and other expenses.

Beginning April 24, 2017, Missourians with disabilities will be able to sign up for MO ABLE tax-advantaged savings accounts without having to risk losing federal benefits. For additional information visit the Missouri Achieving a Better Life Experience (MO ABLE) website at: www.treasurer.mo.gov/content/achieving-a-better-life-experience.

Because this is a brand new law, before making any decisions, become educated with all of the specifics and consequences of the law. Some of the funds may have to be repaid from the accounts upon the death of the person for whom the account was made.

MISSOURI HOUSE BILL 626 – REVISION OF GUARDIANSHIP LAWS

<http://www.house.mo.gov/billtracking/bills171/hlbillspdf/1115H.01I.pdf>

House Bill 626, introduced by Representative Jim Neely, revises Missouri guardianship laws. Guardianship could be weakened. Some of the new wording is concerning. One of these is page 22, line 39: (3) "The guardian shall give priority to home or community-based settings when not inconsistent with the ward's goals and preferences;"

COMMENT: A guardian should not be forced by law to give priority to home or community-based settings. This goes against federal and state laws protecting the right of the guardian to choose from all available living options, not giving preference to any of them. 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.

Last action as of this printing: 3/13/2017 Referred to House Judiciary



MISSOURI SENATE BILL 28-CHANGING MISSOURI MEDICAID PROGRAM TO GLOBAL WAIVER

Introduced by Senator David Sater, Senate Bill 28 would make major changes to how MO HealthNet (Missouri's Medicaid program) is structured.

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 60%.

SB 28 would work like a block grant or per capita cap, 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. The following article describes Medicaid block grants and per capita caps.

This bill has not passed as of 4-27-17.

UNDERSTANDING MEDICAID BLOCK GRANTS AND PER CAPITA CAPS

There are many suggestions on the state and federal level to change the structure of the entire Medicaid program in order to save money. Two of the proposals are block grants and per capita caps. Below is one explanation of these proposals and how it would affect Medicaid recipients.

Henry Kaiser Family Foundation

www.kff.org/medicaid/issue-brief/5-key-questions-medicaid-block-grants-per-capita-caps

What Medicaid Financing Changes are currently being considered?

President Trump and other GOP leaders have called for fundamental changes in Medicaid financing that could limit federal financing for Medicaid through a block grant or a per capita cap. Unlike current law where eligible individuals have an entitlement to coverage and states are guaranteed federal matching dollars with no pre-set limit, the proposals under consideration could eliminate both the entitlement and the guaranteed match to achieve budget savings and to make federal funding more predictable. To achieve budget savings, federal funding limits would be set at levels below expected levels if current law were to stay in place. In exchange for these federal caps, proposals could allow states to eliminate the entitlement to coverage and impose enrollment caps or waiting lists or reduce eligibility levels or offer states other increased flexibility to design and administer their programs. Many proposals do not specify the rules for state matching payments or what core federal eligibility and coverage standards would be changed.

How would a block grant work?

Under a block grant, states would receive a pre-set amount of funding for Medicaid. Typically, a base year of Medicaid spending would be established and then the cap would increase by a specified amount each year, typically tied to inflation or inflation plus some percentage. To generate federal savings, the total amount of federal spending would be less than what is expected under current law. Under current law, federal Medicaid spending matches states spending for eligible beneficiaries and services without a pre-set limit. If state spending increases due to increased enrollment or program costs, then federal spending increases as well. Under a block grant, if program costs exceed the federal spending cap due to increased enrollment during a recession or rise in health costs for example, states would have to increase state spending or reduce enrollment or services.

How would a per capita cap work?

Under a per capita cap, federal funding per enrollee would be capped. A base year of per enrollee spending would be determined and then that amount would increase over time by a pre-set amount (i.e. inflation or inflation plus a percentage). These per enrollee caps could be determined for all enrollees or separate caps could be calculated based on broad Medicaid coverage groups (children, adults, elderly and people with disabilities). States would receive the sum of the per enrollee amounts multiplied by the number of enrollees in each group. To achieve federal savings, per enrollee spending would be set to increase slower than expected under current law. Although this approach adjusts for enrollment it would still not address increases in health costs or changes in technology that increase per enrollee spending.

Capping and reducing federal financing for Medicaid could shift costs to states, beneficiaries, and providers. To respond to reductions in federal funding states could increase state spending to maintain current programs, which would put pressure on other state spending like education. Medicaid already grows at slower rates compared to private health insurance premiums. Most states currently operate programs with low administrative costs and provider reimbursement levels below other payers. Facing federal reductions, states would likely turn to Medicaid program cuts to eligibility, benefits, and reimbursement to providers. These cuts would put populations and providers that disproportionately rely on Medicaid at risk including poor children, the elderly and individuals with disabilities, nursing home and community-based long-term care providers and safety-net hospitals and clinics.



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. 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.

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

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

Knights of Columbus Development Center

3800 Park Ave., St. Louis, MO 63110

314-577-5609

EP MAGAZINE ARTICLE EMPHASIZES THE NEED FOR A FULL CONTINUUM OF CARE FOR PERSONS WITH SEVERE AUTISM

The following is an excerpt from an article published in the April 2017 issue of EP Magazine. It is the last part of the article, telling of one family's persistent efforts to find appropriate services for their severely autistic grandson as his needs changed over the years.

"Our Journey to Find Adequate Resources in the World of Disabilities" 4-2017 EP Magazine
by Joan Kelley, VOR Kansas State Coordinator

"...We had spent 13 years pursuing every community option available, and none provided a lasting solution for Aidan. We were out of community options and had nowhere else to go. So, we turned to what I thought was out of the question for our grandson – a state institution.

We decided to pursue an evaluation and medication wash at the Kansas Neurological Institute (KNI), an Intermediate Care Facility for Individuals with Intellectual Disabilities (ICF/IID). We were not comfortable with the amount of medication Aidan was on, especially since it did not appear to reduce his behaviors. Families like ours had heard for years disparaging remarks about large institutions, and even now, after the community had failed Aidan, the denigration of institutional care did not stop. Everyone we approached in the community system about our intended next step indicated that KNI was not equipped to provide the level of care Aidan required.

We pursued admittance to the Kansas Neurological Institute, knowing little about it, but we were desperate to help our grandson.

The State required us to thoroughly document that we had exhausted every community resource option, which we did for 13 years. However, Aidan's doctor was exceedingly reluctant to sign for his admission to KNI. After a full year of continued pushback, prayers and persistence, Aidan was admitted to KNI on a temporary basis.

The KNI staff were wonderful. They were able to not only safely reduce the years-long, toxic mix of medications from 5 down to one, but KNI had already been incorporating the Person Centered Care Model for a number of years. They developed a comprehensive program for Aidan, which included frequent community outings, exercise, grocery shopping, part time supported employment, etc. while reducing medications and addressing extreme behaviors. Aidan was beginning to live the full life we had always hoped for him.

"Our Journey to Find Adequate Resources in the World of Disabilities" 4-2017 EP Magazine
by Joan Kelley, VOR Kansas State Coordinator continued

The increased structure, expert staff and individually-driven services worked so well, and we were delighted to see Aidan's behavior improve. He was happy, being integrated and supported, as appropriate for his needs. We even looked forward to trying a community setting again closer to our home.

As we looked at community options, we visited several single and duplex group homes. To our surprise, some were so poorly maintained that I would not have wanted to see a pet dog live in them, let alone our precious grandson.

While this was disturbing enough, we were also shocked when numerous community providers refused to serve him! High risk, high staffing ratios and high cost related to his intense behavioral needs, revealed once again that community services, deemed by well-funded DD Act entities as "superior," and the answer once again proving to be a false promise for individuals with the most complex needs. This now clearly included our grandson.

CONCLUSION

Aidan has lived well on a campus of homes at the KNI for almost nine years; this facility has been a God-send to us. Aidan's condition is lifelong. As with many fragile DD individuals affected with the most complex conditions, he needs a level of care that is difficult to find, maintain, and oversee in a fragmented, community system.

The importance of the centralized care model is clearly recognized in our Supreme Court's Olmstead decision. This important level of care however, is being dismantled by community-for-all advocates, most of whom have never lifted a finger to care for such profoundly affected individuals, or endured the pain family members feel, when the much championed, "de-institutionalization" policies lead to untimely deaths.

I believe in community, for those who choose and can benefit from them. I also believe, as most people do, that Intensive Care Units in our hospitals across the nation are a critical part of our health care system. Intermediate Care Facilities (ICFs) are the Intensive Care Units for our DD loved ones.

Shall we devalue the lives of the weakest among us – ignore their unique challenges and needs – by closing the facilities which sustain them? My husband and I say a resounding NO! – joining with thousands of families across the nations, who also know first-hand what it takes to care for our most fragile citizens.

Seeing our loved ones with extreme needs thrive in the setting of THEIR choice is for family members, our just reward for a lifetime of advocacy on their behalf.



PARENT ASSOCIATION COMMENT

The Kansas Neurological Institute is the same as a habilitation center in Missouri.

This article reinforces the need for habilitation centers for some persons with intellectual disabilities, who many times have dangerous behaviors, ongoing medical conditions, and multiple physical impairments.

Habilitation centers excel in several critical areas:

1. availability of medical care, on and off campus
2. accessibility of on campus services such as speech, physical, and occupational therapy
3. variety of programs and work opportunities, on and off campus
4. recreational opportunities, on and off campus

Habilitation centers (ICFs/IID) are residential campuses for persons with intellectual disabilities. They are a real part of the surrounding community of neighborhoods, schools, churches, and businesses.

Habilitation centers are safe, supportive, comprehensive, consistent, cost-effective and sustainable homes for persons who need this level of services.

SHELTERED WORKSHOPS SUPPORTED BY MO SENATORS AND REPRESENTATIVES

Signed into law in 2014, the Workforce Innovation and Opportunity Act (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. Parents of persons working in sheltered workshops are alarmed as evident in the following quote from the Missouri Assn. of Sheltered Workshops. (www.moworkshops.org)

"For parents and others who have found workshops a miracle for their adult children with disabilities, the possibility that workshops would be removed represents a nightmare. Some of these parents, guardians and others remember the dark days before workshops were created. They know from experience that idealistic plans for widespread community employment or expensive alternatives won't work, at least not to the extent needed to provide for nearly 8,000 people in Missouri and hundreds of thousands nationally."

It is good to know that the Missouri Senators and Representatives are in support keeping sheltered workshops running in Missouri as expressed in this Concurrent Resolution:

"Whereas, Missouri residents with disabilities are deserving of having the same choice of where, how, and with whom they work and spend their time as other Missouri residents; and

Whereas, Missouri sheltered workshops, in partnership with business and industry, are an integral part of their local communities and their economies; and

Whereas, programs and employment offered by Missouri's sheltered workshops, through projects contracted at their facilities, supported enclaves, contracts at Missouri's rest stops, employment through AbilityOne contracts, and independent work assignments provide Missouri residents with disabilities the opportunity to meet new people, gain new skills, and earn the respect, dignity, and other ancillary human benefits that come with earning a paycheck and making a contribution to society; and

Whereas, approximately 6,000 Missouri residents with disabilities avail themselves of the opportunity to participate in these programs and related employment; and

Whereas, the parents, guardians, and caregivers of many of these participants support and attest to the benefits of these programs and the employment provided under them; and

Whereas, individuals with disabilities should be free to choose the settings in which they receive services or employment, including programs and employment offered by Missouri's sheltered workshops through projects contracted at their facilities, supported enclaves, contracts at Missouri's rest stops, employment through AbilityOne contracts, and independent work assignments:

Now Therefore Be It Resolved by the members of the Missouri Senate, Ninety-ninth General Assembly, First Regular Session, the House of Representatives concurring therein, hereby reaffirm Missouri's support of the services of the sheltered workshops of our state."

PARENT ASSN COMMENT:

Individuals working in sheltered workshops and their families 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.

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

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THE 2017 VOR ANNUAL CONFERENCE AND CONGRESSIONAL VISITS will be from Saturday, June 3 – Wednesday June 7. The theme this year is "Protecting Individual Rights Through Olmstead Choice".

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 – be a voice for intellectually disabled persons. If you cannot attend, be a sponsor. For more information go to www.vor.net

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
SHOP TILL YOU DROP!! BEST THRIFT SHOP PRICES!!**

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

WEDNESDAYS, 10 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
CORRECTION REQUESTED**