

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

PHONE 314-264-9101 BHC Switchboard
PHONE 314-340-6002 Thrift Shop
WEBSITE www.parentsassociationbhc.com

HAPPY THANKSGIVING



NEWSLETTER NOVEMBER 2023

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.

MEETING DATE: SUNDAY, NOVEMBER 12, 2023

MEETING TIME: 2:00 P.M.

MEETING PLACE: ADMINISTRATION BUILDING

**ELECTION OF OFFICERS AND DIRECTORS
FOR 2024 PARENTS ASSOCIATION**

2024 MEETING DATES – MARK YOUR CALENDARS

FEBRUARY 11 MAY 19 AUGUST 11 NOVEMBER 10

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

Our Parent Newsletter is online at www.ParentsAssociationBHC.com. Pass it along to others.

The Hidden Treasure Thrift Shop is re-opened for business on Wednesdays, from 10:00-3:00!

Find your treasure from: clothes, shoes, household furnishings, toys, books, DVD's, electronics, glassware, kitchen accessories, baskets, electronics, jewelry, holiday decorations, and much more.

Federal Surveyors for Title 19 Medicaid funding were on campus August 20-24. At a revisit on September 25-27 all corrections were satisfied. These requirements give our family members a high level of services and oversight.

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

Because this Supreme Court decision is being misused across the nation to close homes like habilitation centers, the tragic reality is that individuals with intellectual disabilities are lingering in hospitals, jails, homeless shelters, and nursing homes.

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> |
|----------------------------|-------------------------|-------------------------|
| Fred Brueggemann | | donation |
| Richard & Patricia Gill | | donation |
| Jean Barrett | Coll family | in memory of Betty Coll |
| Higginsville Parents Assn. | Coll family | in memory of Betty Coll |
| Kidwell family | Coll family | in memory of Betty Coll |
| Maureen Mueller | Coll family | in memory of Betty Coll |
| Becky Post | Coll family | in memory of Betty Coll |
| Patricia Stevens | Coll family | in memory of Betty Coll |
| Steve & Mary Vitale | Coll family | in memory of Betty Coll |



The BHC Parents Association sends sincere condolences to the Coll family upon the death of Betty Coll who dedicated her life to advocating for the residents of BHC.

Betty was one of the founding members of the Parents Association and of the Thrift Shop. She also headed the statewide organization, RAM, for many years.

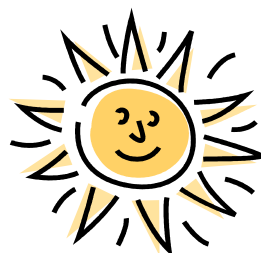
Over the years, she lobbied Congressional members in Washington, D.C., Missouri state legislators, and local policy makers.

Betty could be found at the Thrift Shop several days a week organizing items for the Wednesday sale days. Sales from the Thrift Shop have provided thousands of dollars to support the BHC residents.

She deeply cared for all the residents. Betty will be greatly missed by all of BHC.

FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$ 1000.00 Halloween festivities



THE HIDDEN TREASURE THRIFT SHOP HAS RE-OPENED FOR BUSINESS!

The Thrift Shop is open every Wednesday, from 10:00 a.m. to 3:00 p.m. in building 1901, first building on the left. Come and find some special bargains from a wide variety of items:

clothes, shoes, household furnishings, toys, books, dvds, electronics, glassware, kitchen accessories, baskets, electronics, jewelry, holiday decorations, and much more.

The profits from the Thrift Shop support extra activities for the residents of BHC.

ANNUAL BHC PICNIC SEPTEMBER 2023

The “Under the Sea” themed BHC picnic had perfect weather for watching the parade of floats.

The whirl of bubbles throughout the air from the Bubble Bus added to the fun atmosphere for the residents.

The gym was creatively decorated with balloons, table settings, and “Under the Sea” creatures.

Residents enjoyed Hawaiian Ice, cotton candy, ice cream, funnel cakes, fresh fruit and water.

Fun activities included sitting for a caricature artist picture, watching a balloon artist create balloon characters to be given to the residents, and having faces painted with what residents chose.

Music, dancing, crafts, and games added to the festivities throughout the day,

THANKS to BHC Parent’s Association, BHC Staff, BHC Picnic Committee, Parade Participants, Bubble Bus, Premier Entertainment, D&T Funnel Cakes, Sports Energizers, Terry Hobbs



BHC RESIDENTS ENJOY ACTIVITIES/ SUMMER & FALL

Thanks to staff for helping residents enjoy all of these Summer and Fall activities:

On Campus

Fun in the Sun Outdoor Program- music, games, arts & crafts – outside Multi-Purpose Building

AUGUST- Luau Themed Party – Residents enjoyed Mango Mousse and cupcakes. They danced to great music along with crafts and games.

SEPTEMBER – Annual BHC picnic, “Under the Sea” theme

OCTOBER- Halloween dance and Pumpkin Contest - At the dance, refreshments included Candy Corn Pudding, Pistachio Pudding, Halloween cupcakes, sugar free Pumpkin Pie, Monster Cookies, Brownies and Punch. All residents received a bag of treats. Music, dancing, crafts and games filled the party with fun activities.

BHC Theater featured the movie “The Champions”.

Evening Activities are ongoing: Bingo, Open Gym, Movie Night and Dances.

Off Campus

Home visits, Church worship, Car show, and Annual “Real Voices Real Choices” Conference @ Lake of the Ozarks, Creve Coeur Park

Great Clips, Beauty Supply, Kohl’s, Sonic, Shake Shack, Hawaiian Brothers, Five Guys



BHC ANNUAL FEDERAL SURVEY

Federal surveyors for Title 19 of the federal Medicaid law were on the BHC campus from August 20-August 24. These annual surveys help to ensure high quality care and services for BHC residents.

The federal surveys of habilitation centers must meet 8 Conditions of Participation: (CoPs):

1. Management
2. Client Protections
3. Facility Staffing
4. Active Treatment
5. Client Behavior and Facility Practices
6. Health Care Services
7. Physical Environment
8. Dietetic Services



The eight CoPs comprise over 400 specific standards and elements. Serious deficiencies must be corrected within 90 days; other deficiencies must be corrected within a year. Failure to correct deficiencies results in loss of certification and loss of Medicaid funding.

2023 FEDERAL REIMBURSEMENT FUNDS TO THE STATE OF MISSOURI

| HABILITATION CENTER | FY 2021 ICF/IID COLLECTIONS | \$ |
|--|---|----|
| Bellefontaine | \$17,718,728.13 | |
| Higginsville | 9,482,896.53 | |
| SEMORS | 9,144,929.73 | |
| St. Louis DDTTC (St. Charles, S. County) | 17,266,762.98 | |
| TOTAL | 53,613,317.37 for habilitation centers | |

Habilitation centers continue to earn millions of dollars in federal Medicaid reimbursement funds for the state of Missouri at the rate of approximately \$65.00 for each \$100.00 of expenditure for habilitation center services!!!

Habilitation centers are successful, stable, and sustainable, giving comprehensive, consistent, and cost-effective care to the residents. Receiving comparable services “in the community” would not save money.

Families are calling BHC looking for services, but are denied the choice of a habilitation center which is their federal legal and civil right. Do you know of a family that might need the services of a habilitation center? Call the Parents Association at 314-264-9100 or 314-340-6002.

FEDERAL REIMBURSEMENTS FOR STATE OPERATED HOMES IN THE COMMUNITY

Because these homes are state operated, the state of Missouri also receives federal reimbursements for them.

| | |
|------------------------------|---|
| Northwest Community Services | \$12,517,009.83 |
| Southwest Community Services | 5,256,040.26 |
| TOTAL | 17,773,050.09 for state operated community homes |

THE FOLLOWING TWO ARTICLES ADDRESS THE BASIC REAL NEEDS OF DAILY LIVING FOR PEOPLE WITH DISABILITIES

ADULT SIZE CHANGING TABLES IN PUBLIC AREAS – MINNESOTA

<https://www.disabilityscoop.com/2023/04/04/parents-push-adult-size-changing-tables-public-restrooms/30322/>

by Chris Serres, Star Tribune/TNS | April 4, 2023

MINNEAPOLIS — Tram Nguyen has used restroom floors, the grass at city parks and the back of her van to change her 7-year-old daughter's diapers.

Her daughter, Sadie, who was born with a chromosomal abnormality that limits her mobility, has outgrown the infant changing tables in most public restrooms.

"It's disgusting and undignified to have to lay your daughter on a bathroom floor," said Nguyen, a former retail executive and stay-at-home mother from Minneapolis. "My daughter needs to get out in the community, and not having a safe, private place to change her diapers is a major obstacle."

Nguyen has joined a burgeoning campaign to make public restrooms more accessible to larger children and adults who have difficulty using toilets because of their disabilities.

ADULT CHANGING TABLES ARE NOW MINNESOTA LAW IN ALL NEW PUBLIC RESTROOMS

<https://www.cbsnews.com/5minnesota/news/adult-changing-tables-are-now-minnesota-law-in-all-new-public-restrooms/>

By Susan-Elizabeth Littlefield May 30, 2023 / 7:50 PM / CBS Minnesota

MINNEAPOLIS – A number of Minnesotans are celebrating a big win, as adult changing tables are now law in new public spaces that are built in Minnesota.

As WCCO has previously reported, some Minnesotans say using public restrooms has been a dehumanizing and disgusting experience, as they are forced to lie on the floor.

When Linda Hood, a marathoner who lost the use of her legs from a virus, became Miss Wheelchair Minnesota in early 2022, she declared it her mission to get adult changing tables in public restrooms.

She joined forces with Sarah St. Louis, who was struggling to change her beloved son Ezra, who has a traumatic brain injury and was too big for infant tables.

"The only places we had to change him were dirty public restroom floors. I realized that this is really undignified, it's not sanitary, it's not safe and it's humiliating to put your child on a dirty bathroom floor," St. Louis said.

Four years ago, she took on the momentous task of changing the law alongside advocates like Hood, who never gave up.

"We got Sen. Liz Bolden and Rep. Kim Hicks to be respective authors. They spent about 15 hours over two days, and they finally voted 34 to 33 to pass it on. Just after midnight, they passed it, and then we got Gov. Walz to sign it last week," Hood said.

She added it was quite emotional.

"It just, it makes tears fall, it just makes tears fall," Hood said.

"When I got home, I showed my son, and he was like, 'He signed it?' And I was like, 'Yes baby, he did!' He goes, 'We just changed the world!'" St. Louis said. "It just made me realize that we did something that meant something. We brought human dignity to Minnesota, finally."

Hood said this most recent development won't be the end of the story, either.

"I thought this is Minnesota and we did it, we have to make it possible for the other states," Hood said. "This is just the beginning, the beginning."

The new law is set to go into effect in January. It will mean any large public buildings like movie theatres, malls, and stadiums will have to be built with adult changing tables. There is also up to \$20,000 in incentives for existing businesses to update their restrooms, too.

OLDER PEOPLE WITH INTELLECTUAL DISABILITIES WITH AGING CAREGIVERS – WHERE WILL THEY LIVE?

Medicaid Aims To Better Serve Adults With IDD, Aging Caregivers

<https://www.disabilitycoop.com/2023/06/22/medicaid-aims-to-better-serve-adults-with-idd-aging-caregivers/30435/>

by Michelle Diament | June 22, 2023

Upwards of a million U.S. households include an adult with intellectual and developmental disabilities who's supported by an aging caregiver and that number is expected to grow. Now, Medicaid officials are making a push to better meet their needs.

The Centers for Medicare and Medicaid Services is issuing a collection of new resources to help state Medicaid and partner agencies as they design and deliver services for this burgeoning demographic.

Across four documents, the agency is offering guidance on how states can anticipate the needs of adults with IDD and their caregivers as they get older and tips on devising policies and practices to support these needs and promote person-centered planning.

In addition, CMS is highlighting innovative strategies that states are already employing that could be replicated in other places.

The documents point to various data sources including Social Security's Disabled Adult Child program, which many adults with developmental disabilities qualify for, that could help states forecast future demand for home and community-based services. CMS is also encouraging states to consider outreach to caregivers and other strategies such as reserving slots in their Medicaid waiver program for people with IDD who have aging caregivers.

With the shift away from institutions in recent decades, the needs of adults with developmental disabilities and their aging caregivers are becoming more urgent, officials said. They cite data showing that between 1998 and 2018, the number of people with IDD who received Medicaid home and community-based services while living with family jumped 143%.

Moreover, officials noted that of the 7.43 million people with IDD estimated to be in the U.S. as of 2018, only 21% were receiving services from or otherwise known to their state IDD agency.

"People with I/DD not currently served by state I/DD agencies may first interact with state systems when they are in crisis (e.g., after a parent's sudden death or decline in health) and, as a result of their urgent circumstances, may end up with less desirable and/or more costly services," according to information in the new resource documents. "State Medicaid and partner agencies can better support adults with I/DD who have aging caregivers by proactively planning in the present and for the future, when new supports are needed, and, when possible, before a crisis happens."

PARENT ASSOCIATION COMMENTS:

The Centers for Medicare and Medicaid (CMS) acknowledges that there is an older caregiver crisis and an increased population of aging of people with intellectual disabilities. An important resource for those looking for services is the federal program of intermediate care facilities for individuals with intellectual disabilities (ICFs/IDD) which are habilitation centers in Missouri. Sadly, for Missouri families, there is a No New Admissions policy for habilitation centers despite the federal right to choose this option.

ICFs/IDD have an expertise to support people with intellectual disabilities. They are successful, stable, and sustainable, giving comprehensive, consistent, and cost-effective care to the residents. These facilities 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

5. a high level of oversight

AMY S. F. LUTZ, PHD HAS A NEW BOOK IN SUPPORT OF NEEDED SERVICES

Chasing the Intact Mind – How the Severely Autistic and Intellectually Disabled Were Excluded from the Debates That Affect Them Most by Amy S.F. Lutz, was just published in October 2023.

Three major issues concerning people with severe autism and intellectual disabilities are covered in this book – support for 14c sheltered workshops, guardianship for those who need that level of assistance and protection, and lack of evidence for facilitated communication success.

Dr. Lutz is a founding member and vice-president of the National Council on Severe Autism (NCSA). Her advocacy is to affect public policy decisions that recognize the real needs of people with severe autism and cognitive impairment.

Her writing about severe autism has been featured on many platforms, including Psychology Today, The Atlantic, Slate, and Spectrum. Her first book, *Each Day I Like It Better: Autism, ECT, and the Treatment of Our Most Impaired Children*, was published in 2014. Her second book, a collection of essays called *We Walk: Life with Severe Autism*, was published in 2020.

Go to You Tube to listen to her discussion of the book and the issues it covers.
<https://www.youtube.com/watch?v=H1vkjuw6eUc>

VOR (VOICE OF REASON) ADVOCACY

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

VOR's Second Legislative Initiative - October, 2023

<https://vor.net/legislative-voice/item/vor-s-second-legislative-initiative-october-2023>

VOR has been conducting another Legislative Initiative, sending documents outlining our families' concerns for:

- the ongoing critical shortage of Direct Support Professionals, and
- the movement to eliminate Section 14(c) employment opportunities.

Materials that are being shared with congressional staffers can be found at www.vor.net

1. Overview of our Legislative Concerns
2. Addressing the DD Workforce Crisis
3. Supporting Employment Opportunities for People with I/DD and Autism



ADVOCATE FOR FAMILY CHOICE!!

MAKE A DIFFERENCE - BECOME A VOR MEMBER online at www.vor.net
JOIN VOR \$45 per year per individual; \$200 per year per family organization; or \$250 per year per provider/professional organization

Send completed form with payment to: (checks made out to "VOR")

VOR
836 S. Arlington Heights Rd., #351
Elk Grove Village, IL 60007

Name: _____
Address: _____
City: _____

State: _____ Zip _____

Home Phone: _____

E-Mail: _____

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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



GRAND REOPENING



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, 10:00 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