

**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

NEWSLETTER AUGUST 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, AUGUST 13, 2023

MEETING TIME: 2:00 P.M.

MEETING PLACE: ADMINISTRATION BUILDING

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 preparing to re-open!

Volunteers are needed to staff the Thrift Shop if we are going to be able to open. Please call the BHC switchboard, 314-264-9101, to leave your name and number.

The 100th anniversary of the Bellefontaine Habilitation Center will be held in June 2024. See page 2 for more information, and [how to respond if you are going to attend](#).

Direct Support Professional Week will be celebrated the week of September 9-16. Thank staff for all the work they do to help our family members with their daily living needs.

The national organization VOR held its annual Legislative Initiative in May and June by Zoom meetings and conference calls with U.S. Congressional offices. The annual Membership Meeting was held on June 11 with excellent speakers. Members from several states attended the meeting.

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:

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

Keep informed, take action,

Mary A. Vitale, President, Bellefontaine Parents Association

TRIBUTE FUND

Celebrate a birthday or anniversary, offer get well wishes or congratulations, remember a loved one by sending in a tribute - support the residents at Bellefontaine Habilitation Center. A few examples of the use of funds are: annual picnic, Christmas gifts and decorations, birthday cakes and presents, holiday decorations, treats and dances, household items, and special programs. The tribute form is on the last page of the newsletter.

DONOR

Mike & Doris Brophy

RECIPIENT

Angel Brophy

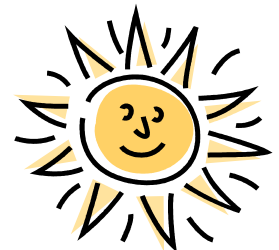
OCCASION

in memory of Steven Brophy



FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$ 1200.00 Birthday gifts for residents July-December 2023
\$ 6500.00 BHC Annual Picnic



THANK YOU TO KNIGHTS OF COLUMBUS, DE ANDREIS COUNCIL 880

FOR A GENEROUS DONATION TO THE BHC PARENTS ASSOCIATION IN SUPPORT OF
ACTIVITIES FOR BHC RESIDENTS



100TH ANNIVERSARY CELEBRATION



SAVE THE DATE/INVITATION

PLEASE PLAN TO ATTEND

**THE BELLEFONTAINE HABILITATION CENTER
CENTENNIAL CELEBRATION**

TO BE HELD JUNE 13, 2024

**THERE WILL BE A CEREMONY IN THE GYM BEGINNING
AT 11:00 AM, FOLLOWED IMMEDIATLY BY LUNCH.**

COME EARLY TO ENJOY MUSIC BY “MORNING THUNDER”

PLEASE RSVP BY August 31, 2023

**CONTACT: Bill Heuvelman at 314-264-9140, or E-MAIL
Bill.Heuvelman@dmh.mo.gov**

ANNUAL BHC PICNIC, THURSDAY, SEPTEMBER 14, 2023

The annual BHC picnic is once again being held in the gym.

Date: Thursday, September 14, 2023.

Theme: Under the Sea

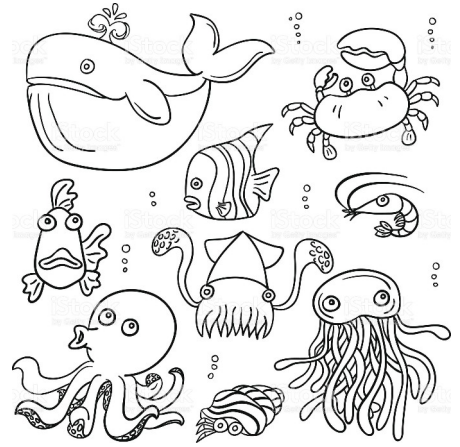
Parade: 9:30am

Picnic activities in the gym are in two sessions:

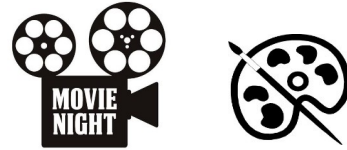
The morning group is 10:00-11:30. (1502 1503 1504 1505 1601 1610)

The afternoon group is 1:30-3:00. (1603 1604 1606 1607 1608 1908 Apt B)

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



BHC RESIDENTS ENJOY ACTIVITIES/SPRING AND SUMMER



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

On Campus Activities:



MAY: At the Spring Party in May residents had games to play, Sun Catchers to design, and music to dance to. They enjoyed Lemon Mousse and lemon cake.

JUNE: The Juneteenth Party was enjoyed by the residents as they designed Canvas Drawstring Bags, danced to music, and played games. Refreshments served were apple cobbler and cupcakes.

JULY: There was great music at the Independence Party. Each resident had a baseball cap to design. Strawberry shortcake and punch were served.

SUMMER: Fun in the Sun Outdoor Program- Twice a week two homes have Art Crafts and Games during morning hours outside the Multi-Purpose Building.

EVENING: Activities are Movies, Bingo, Open gym and Dances.

BHC THEATER is back: Morning Movies will be shown in the Gym once again.



FISHING at Bellefontaine Conservation gave residents a fun way to be outdoors.

ARTWORK of BHC resident participants of Missouri Showcase is now displayed at BHC.

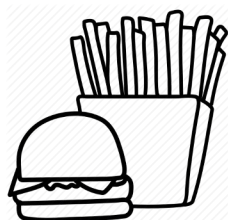
Off Campus Activities:

Home visits, Church worship, library, trip to the Ozarks



Shopping- Game Stop, Walmart, Burlington, Target, Shoe Carnival, Family Dollar, Dollar Tree and Aldi's.

Restaurants- Qudoba, Subway, Mc Donald's, Steak N Shake, Fazoli's, Dairy Queen, Red Lobster, Bus Loop Burgers, Olive Garden, White Castle, St. Louis Fish and Chicken, Chili's, Culver, Burger King and Golden Corral.



OHIO PROTECTION AND ADVOCACY AGENCY FOUND LACKING IN PROTECTION

Every state has a Protection and Advocacy Agency (P&A) as required by federal law, the 1975 Developmental Disabilities Assistance and Bill of Rights Act (DD Act). The purpose of P&As is to protect of the rights of persons with disabilities, including people with developmental and intellectual disabilities.

However, many times the P&As have policies to encourage the closure of intermediate care facilities like habilitation centers and sheltered workshops against the choice of families to use these services.

Ohio has a law that states: **“Every two years, the president of the senate and speaker of the house of representatives shall establish a joint committee to examine the activities of the state’s protection and advocacy system and client assistance program.” Section 5123.603 - Ohio Revised Code**

In November 2022, hearings were held by the Joint Committee to Examine the Activities of Ohio's Protection and Advocacy (P&A) System and Client Assistance Program (CAP). The Joint Committee accepted testimony from families of individuals with disabilities who receive critical care and support in Intermediate Care Facilities for Individuals with Intellectual Disabilities (ICFs), sheltered workshops, and facility-based day programs.

Ohio families testified about their dissatisfaction with Ohio’s P&A, Disability Rights Ohio, (DRO) because of DRO's actions and biases against people using these services.

In April 2023 the Joint Committee published a report summarizing the findings from the hearings and testimonies. The following quote is from the report.

“Despite being Ohio’s P&A and CAP, with the responsibility to protect the rights of individuals with disabilities, the testimony given by parents, guardians, and family members expressed concerns over DRO’s administration of its service system. Specifically, the testimony described DRO’s excessive litigation against the State to which families objected. It also described DRO’s efforts to promote transfers of residents out of ICFs, sheltered workshops, and facility-based day programs into community settings without regard to individual choice and parental rights. Those efforts included DRO staff meeting privately with ICF residents without their guardians or parents present to encourage them to leave their ICF placement.”

The report concludes with a number of recommendations including:
(emphasis added)

Section 4 Joint Committee Recommendations

“1. Redesignate the current P&A agency for **intentionally not protecting and advocating for all individuals with disabilities.** In particular, the current P&A is not protecting or advocating for individuals residing in ICFs and/or accessing sheltered workshops, and facility-based work and day programs. When the joint committee questioned DRO about this concern, DRO indicated it does not have the resources to help everyone. The joint committee understands that DRO cannot provide individual legal representation to every individual served by the system, but **it can protect all interests by promoting all service options through its advocacy with policymakers and by respecting the diverse choices made by individuals and families in the system.**”

MISSOURI PROTECTION AND ADVOCACY SERVICES ALSO LACKING?

The Missouri Protection and Advocacy Services has many times supported the closings of habilitation centers and sheltered workshops. Their Objectives and Priorities states:

Priority #5 - DD Network Partner Collaboration Systemic Initiatives

Mo P&A will monitor and seek changes to Missouri’s:

1. Sheltered workshop employment practices,
2. DESE state school operations, and
3. DMH habilitation center operations.

For more information go to:

<https://www.moadvocacy.org/padd-statement-of-objectives-and-priorities?rq=objectives>

AUGUST 2023 PAGE 5

RECOGNITION OF PROFOUND AUTISM

Profound Autism' Accounts For More Than 1 In 4 Cases, CDC Finds

by Michelle Diament | April 24, 2023

<https://www.disabilitycoop.com/2023/04/24/profound-autism-accounts-for-more-than-1-in-4-cases-cdc-finds/30348/>

With a new report, the Centers for Disease Control and Prevention is tacitly embracing a recently coined autism classification and providing a first-of-its-kind breakdown on the number of kids on the severe versus milder ends of the spectrum.

Researchers from the federal health agency published a study this month in the journal Public Health Reports indicating that 26.7% of children with autism have what's known as "profound autism," meaning that they are nonverbal, minimally verbal or have an intelligence quotient of less than 50.

Other kids with the developmental disability have more mild presentations, the study found.

The term profound autism is new, with an international panel of experts first calling for the distinction in an article published in The Lancet in late 2021. They argued that the needs of people on the spectrum who require 24-hour care are being obscured by being lumped into the same diagnostic category as individuals who are capable of earning college degrees.

The latest research is based on data collected through the CDC's Autism and Developmental Disabilities Monitoring Network, which regularly conducts surveillance on the prevalence of autism among 8-year-olds in select communities across the country. For the study, researchers looked at information from 20,135 kids with autism across 15 sites who were age 8 between 2000 and 2016.

"We saw this as an opportunity to use CDC's ADDM Network data to bring data to the discourse around profound autism to better describe those who met The Lancet commission's profound autism criteria and changes in prevalence over time," said Michelle Hughes, an epidemiologist at the CDC's National Center on Birth Defects and Developmental Disabilities who led the study.

The study found that the prevalence of both profound and non-profound autism grew over time, but the increase was more substantial for children with milder presentations.

"This means that over time, there has been a lower proportional representation of those with profound autism compared to those with non-profound autism," Hughes said.

Kids with profound autism were more likely to be girls, be from racial and ethnic minority groups and come from households with lower socioeconomic status, the researchers found. These children also were more commonly born early or at low birth weight and to have self-injurious behaviors, seizure disorders and lower adaptive scores.

"We need to know how many people have profound autism so that we can properly plan for their school and residential needs and improve the services they receive," said Alison Singer, president of the Autism Science Foundation and a co-author of the new report and a member of The Lancet commission. "Their needs are going to be very different than those of an autistic person graduating from Harvard Law School."

But not everyone is happy to see the CDC and others using the classification of profound autism.

"While I think it is fine for the CDC to analyze how many people in their autistic sample are nonspeaking or have intellectual disabilities, even among and between those groups, people's support needs and how their disabilities affect them can dramatically vary," said Zoe Gross, director of advocacy at the Autistic Self Advocacy Network. "We are concerned to see the CDC using a term like profound autism, especially given the lack of an evidence base for autism subtypes."

A PARAGRAPH FROM PRECEDING ARTICLE WORTH REPEATING

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commission. “Their needs are going to be very different than those of an autistic person graduating from Harvard Law School.”

AUGUST 2023 PAGE 6

PEOPLE WITH PROFOUND AUTISM: WHERE WILL THEY LIVE?

The following article shows that families want facility-based care.

Laredo mother emphasizes the need for residential facility for adults with severe autism

By [Brenda Camacho](#) Updated: May. 14, 2023 at 10:00 PM CDT

<https://www.kgns.tv/2023/05/15/laredo-mother-emphasizes-need-residential-facility-adults-with-severe-autism/>

LAREDO, Tex. (KGNS) - A Laredo mother is fighting for the future of her two young adult children who are navigating life with severe autism.

As Victoria “Vicky” Gonzalez and her children grow older, so does the concern about what will happen to them once she and her husband pass away.

Vicky reached out to the ‘KGNS On Your Side’ team to inquire about the establishment of a residential facility, where people with severe autism can live an independent lifestyle, in the Laredo/Webb County community.

“This makes it hard really, to enjoy life” Vicky said. “Thinking what’s going to happen to them, and also we want to be able to live in peace and die in peace,” she added. This fear is something Vicky harbors every day because her two kids depend heavily on her and her husband.

Vicky’s son, Mario, 20, and daughter, Isabella, 16, are both on the autism disorder spectrum and struggle with verbal communication.

According to [autismspeaks.org](#), an estimated 25% to 30% of people with autism are diagnosed as nonverbal or minimally verbal, which is what Mario and Isabel have.

“In the case of my son,” Vicky said. “He cannot say any words he just will grunt; he will use some signs he learned through therapy. He uses a communication device, but, of course, someone needs to be there to charge it for him, so that’s why they cannot live alone. They need a caretaker, they need a place.”

There are nonprofits and businesses in Laredo and Webb County that provide home health care services, but Vicky said she’s interested in having a facility that could be a long-term residential home for adults with severe autism that has enough space for activities that’ll meet their sensory needs.

Aside from worrying about where her kids will end up, Vicky also questions if they’ll stay together and if the family will visit them.

That’s why she hopes to keep them together in their hometown of Laredo, which has their family all around.

“Because the ones that don’t get any visitations are usually the ones that get neglected, abused, I mean, it’s very difficult when they cannot speak to express anything, so if they’re here locally people can drop in here or there, occasionally,” Vicky said.

While it’s a dream to build a center like this, making it a reality is a challenge.

KGNS reached out to some of the top elected officials in the Laredo/Webb County area, and asked, “What would go into a project like this?”

Webb County Judge Tano Tijerina said building facilities like these from the ground up is a challenge but possible.

“I think it’s a great idea but it will be very, very difficult,” Judge Tijerina said. “Not to say that it can’t happen,” he added.

City of Laredo Mayor Dr. Victor Trevino said more funds need to be dedicated to our medically underserved community.

“It takes funding agencies, first of all,” Mayor Trevino said. “We also need to have health agencies. We need to get all the areas involved to make a facility like this,” he added.

Lastly, U.S. Rep. Henry Cuellar, D-Texas, who is co-chair of the Congressional Autism Caucus, said the federal government can provide grants to a project like this. “I can come up with some money that can help either for a construction,” Rep. Cuellar said. “The community needs to tell me this – is where we need to put this earmark,” he added.

It'll likely take a partnership with a for-profit or not-for-profit organization to get a facility like this created. All leaders are in favor of this and agree that more public input and interest will be needed to push the needle on this idea. Recently, Cuellar awarded the City of Laredo Health Department over \$2M for the study of autism in our community.

AUGUST 2023 PAGE 7

VOR ANNUAL CONFERENCE AND VIRTUAL CONGRESSIONAL MEETINGS 2023

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

The 2023 VOR Annual Legislative Initiative with Congressional visits was a virtual event this year, held during the month of May.

The Congressional offices expressed how important these meetings are, as they hear from many disability organizations that want to eliminate homes like habilitation centers.

Material presented to Congressional offices included topics about improving the Safety for People with I/DD and Autism by:

- * Preventing and Reporting Incidents of Abuse and Neglect
- * Promoting the Use of Cameras in Common Areas
- * Holding Protection and Advocacy Agencies Accountable
- * Supporting our Direct Support Professionals



To read the legislative materials go to:

<https://vor.net/news-and-events/item/vor-s-2023-legislative-initiative>

The Annual Conference Membership Meeting was held on June 11, from 10:30 a.m. to 4:30 p.m. central time. Presentations from the guest speakers were very informative on many important current issues concerning services for people with intellectual disabilities.

U.S. Congressman Glenn Grothman from Wisconsin spoke about two bills he introduced in Congress that would protect sheltered workshops. The **Workplace Choice and Flexibility for Individuals with Disabilities Act** would amend the Rehabilitation Act of 1973 to clarify the definition of competitive integrated employment. The **Restoration of Employment Choice for Adults with Disabilities Act** would amend the Rehabilitation Act of 1973 to ensure workplace choice and opportunity for young adults with disabilities. VOR supports both of these bills.

Illinois State Representative Charles (Charlie) Meier (108th District, IL General Assembly) has been a strong supporter of the Murray Center, a state-operated ICF in Southern Illinois. He introduced three bills in the IL General Assembly this year to improve the reporting of incidents of abuse and neglect, initiate a demonstration program to determine the effectiveness of cameras in common areas of facilities for people with I/DD, and to require the state to perform unannounced annual inspections of all of its I/DD facilities.

Amy S. F. Lutz, PhD, is a founding member and vice-president of the National Council on Severe Autism (NCSA). Amy S.F. Lutz's 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. Her new book, *Chasing the Intact Mind - How the Severely Autistic and Intellectually Disabled Were Excluded from the Debates That Affect Them Most* to be published in October 2023.

To access videos of these presentations go to:

<https://vor.net/news-and-events/item/vor-s-2023-annual-meeting-celebrating-40-years>

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

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