

BELLEFONTAINE HABILITATION CENTER PARENTS' ASSOCIATION

10695 BELLEFONTAINE ROAD
ST. LOUIS, MO 63137

PHONE 314-340-6002

WEBSITE www.ParentsAssociationBHC.com

NEWSLETTER

MAY 2013



PARENTS ASSOCIATION MEETING

SUNDAY, MAY 5, 2013 2:00 p.m.

GYM IN THE MULTIPURPOSE BUILDING, BHC

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, email a message, 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.

2013 PARENT ASSOCIATION MEETING DATES – Mark your calendars

MAY 5

AUGUST 11

NOVEMBER 10

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Our Parent Newsletter is online at www.ParentsAssociationBHC.com!! Pass it along to friends, family, and political leaders.

Allowing new long-term admissions to habilitation centers is a major issue for families across the country.

The safety, health, and well-being of the high needs persons now living in habilitation centers are at risk because of the no new admissions policy and the closing of habilitation centers.

The closure of all habilitation centers in Indiana has caused the waiting list to increase to over 19,000 persons according to a 2011 report by Indiana ARC.

U.S. Sen. Chris Murphy is calling for a nationwide investigation into the "alarming number of deaths and cases of abuse" of developmentally disabled individuals at government-financed residential facilities.

The closure of sheltered workshops is also becoming a "trend" of our national policy, along with that of total deinstitutionalization.

Disability Rights Legislative Day was April 9 at the Missouri Capitol. Keep in contact with your legislators to let them know how important habilitation centers are to your family. Contact: Governor Jay Nixon, and Missouri State Senators and Representatives. For contact information

Missouri Capitol Switchboard:

1-573-751-2000

www.mo.gov

The VOR Annual Conference and Congressional meetings will be held in Washington, DC on June 8-12. Mary and Steve Vitale will represent the BHC Parents' Association.

Waitlist for services of as 4-1-2013

154 Residential 1,618 In Home 1,772 Total

Thanks to BHC staff that made sure residents and the campus grounds were well taken care of during two snow storms in the past few months. Your diligence and caring is appreciated.

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	RECIPIENT	OCCASION
Jeanette Craig	Cathy Berkley family	in memory of Cathy Berkley
Howard & Norma Lingle	Cathy Berkley family	in memory of Cathy Berkley
Betty Coll	Dee Baldetti	in memory of Jim Kemp
Jeanette Craig	Dee Baldetti	in memory of Jim Kemp
Maryjane Gamache	Dee Baldetti	in memory of Jim Kemp
Jerome & Gabriella Giuseffi	Dee Baldetti	in memory of Jim Kemp
Tom & Jan Howard	Dee Baldetti	in memory of Jim Kemp
Helen Kemp	Dee Baldetti	in memory of Jim Kemp
Howard & Norma Lingle	Dee Baldetti	in memory of Jim Kemp
Bill & Sarah May	Dee Baldetti	in memory of Jim Kemp
Paul Richter	Dee Baldetti	in memory of Jim Kemp
Mickey Slawson	Dee Baldetti	in memory of Jim Kemp
Steve & Mary Vitale	Dee Baldetti	in memory of Jim Kemp
Jim & Ruth Vondras	Dee Baldetti	in memory of Jim Kemp
Women's Closet Exchange	Dee Baldetti	in memory of Jim Kemp

Our sincerest sympathy goes to the family of Jim Kemp upon his death. Jim's faithful dedication to the residents of BHC greatly helped them have a better life. His hard work will be greatly missed.



FUNDS APPROVED BY PARENTS ASSOCIATION BOARD

\$2,220	Birthday cakes for residents 2013
300	Valentine candy
300	Easter candy
200	Household goods, home 1502
200	Household goods, home 1603
200	Household goods, home 1609
200	Household goods, home 1610
200	Household goods, home 1807



RAM DUES FOR 2013

The Mental Retardation Association of Missouri (RAM) requests your support for RAM's efforts on behalf of all state habilitation centers in Missouri. Annual dues are \$5.00. Please make checks payable to RAM and mail to: Norma Lingle 1010 DuBerry Lane St. Louis, MO 63138

PARENT ASSOCIATION MEMBERSHIP DUES FOR YEAR 2013

Dues are \$5.00 a year. Make checks payable to BHC Parents' Association, Inc.

Mail to: JOHN AHLQUIST
7711 Bonhomme
Ste 850
Clayton Mo 63105

If you are a new member, please let us know so that you can receive our newsletter.

Our newsletter is also online at www.ParentsAssociationBHC.com

PUBLIC COMMENT SENT TO NATIONAL COUNCIL OF DISABILITY ((NCD)

NCD is an independent federal agency charged with advising the President, Congress, and other federal agencies regarding policies, programs, practices, and procedures that affect people with disabilities.

The current NCD policy paper and how-to manual entitled "*Deinstitutionalization: Unfinished Business*" calls for closure of all large and small habilitation centers.

The following comments were sent in opposition to this deinstitutionalization policy:

February 5, 2013

National Council on Disability Jan. 29, 2013 NCD Quarterly Meeting

Please provide each NCD Council Member with a copy of these comments.

The following comments express my strongest opposition to the policy document "*Deinstitutionalization: Unfinished Business*" and the how-to manual.

The specialized care available at intermediate care facilities for the mentally retarded (ICFs/MR) is comprehensive and cost-effective. The population that remains at these homes are persons with the highest degree of physical, mental, and behavioral impairments.

These ICFs/MR excel in:

- 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. strict service and oversight regulations
- 6. being a part of the surrounding community

These centers are successful, stable, and sustainable. Instead of calling for closing them all, they could be used as long term homes for those who need a high level of care, and as a resource center of specialized care for those who are capable of living more independently.

Current laws and the 1999 Olmstead Supreme court decision support more choice, and do not call for the closure of anything.

Give serious thought to the fact that your current official capacity may change in a few years, but the decisions you make about the closures of ICFs/MR will last a lifetime for the residents who are thriving in them today.

The current residents of ICF/MR homes need and deserve the level of care provided in these centers to continue to live a decent life and die a natural death, not death caused by lack of proper care.

Closing these centers is truly like pulling the plug on the life support system needed by these residents over the objections of loving families, resulting in avoidable death, abuse, and neglect.

Respectfully,
Mary A. Vitale, President, Bellefontaine Parents' Association

To read the full report, go to WWW.NCD.GOV

TAKE ACTION: Individuals may provide public comment by sending their comments to **PublicComment@ncd.gov**, using the subject line of ``Public Comment.'

202-272-2004 (Voice)

202-272-2074 (TTY)

202-272-2022 (Fax)



WHAT IF? IDEAS TO THINK ABOUT from VOR, vor.net

What if seniors in a picturesque retirement community were forced to relocate into scattered homes across a city because advocates successfully closed the retirement community on the grounds that the seniors' congregate, specialized services and amenities were too "institutional." Seniors protested, but their voice didn't matter.

What if parents of elementary school students read in the newspaper that their children were plaintiffs in a lawsuit involving the closing of their school? The parents protested, but their voice didn't matter.

What if hospitals closed intensive care units (ICU) in favor of home-based health care, despite the fact that medically-fragile people would be isolated from the specialized care they required and health care costs would skyrocket? Patients and their families protested, but their voice didn't matter.

If these examples were true, citizens would be outraged and come to the support of these seniors, parents, and patients.

Yet, this same scenario, through aggressive "deinstitutionalization," is impacting individuals with intellectual and developmental disabilities (I/DD), removing these fragile individuals from their homes, without regard to choice, need, or input from them or their families. Parent and family fear is understandable. There are widespread, well- documented tragedies following closures. These tragedies are predictable because needs are remarkably profound.

INDIANA: RESULTS OF HABILITATION CENTER CLOSURES (INTERMEDIATE CARE FACILITIES FOR THE MENTALLY RETARDED, ICF/MR) from VOR, vor.net

In 2011, an Indiana Arc task force report found that the waiting list had grown to over 19,000 people, some who waited more than 12 years. The dearth of specialized services in Indiana created this crisis, one that the Indiana Arc expects to be addressed, in part, by family caregivers. However, consistent with our mission in support of high quality care and human rights for all people with intellectual and developmental disabilities, natural supports should not be imposed on families when doing so creates an impossible burden on too few people to the detriment the individual's and the family's mental, physical and financial health, and indeed, risks separating the family unit itself.

FEDERAL LAW REQUIRES CHOICE

Current law states:

CODE OF FEDERAL REGULATIONS 42 CFR 441.302 TITLE 42 PUBLIC HEALTH

CHAPTER IV: CENTERS FOR MEDICARE & MEDICAID SERVICES, DEPARTMENT OF HEALTH AND HUMAN SERVICES

(d) Alternatives—Assurance that when a recipient is determined to be likely to require the level of care provided in a hospital, NF, or ICF/MR, the recipient or his or her legal representative will be—

(1) Informed of any feasible alternatives available under the waiver; and

(2) Given the choice of either institutional or home and community-based services

Why is this law being ignored, putting persons with the most severe disabilities in harm's way?



MAINTAINING ICF/MR HABILITATION CENTER HOMES

The following position paper was compiled by Carole Sherman, Public Affairs Chair for Families & Friends of Care Facility Residents (Arkansas' statewide parent-guardian association). There is a national effort to keep ICF/MR habilitation center homes open. Contact: carolelsherman@sbcglobal.net

FAMILIES' RESPONSES TO ASSAULTS AGAINST THEIR LOVED ONES' SAFE ICF/MR* HOMES

* ICFs/MR (Intermediate Care Facilities for persons with Mental Retardation) are licensed, Medicaid-certified programs serving as safe and supportive homes for citizens with a medical diagnosis of profound and severe mental retardation.

1. FALSE: Deinstitutionalization (leaving ICF/MR homes) will cause persons with severe impairments to become more independent and to live nearer their families.

RESPONSE: The reality is that persons with severe cognitive impairments may have less independence for lack of on-site medical care and therapies upon leaving an ICF/MR. These on-site services enable residents to maintain their level of function.

2. FALSE: Deinstitutionalization (downsizing/closing ICF/MR homes) will increase community care options.

RESPONSE: More community care should not come at the expense of dismantling proven systems of care of ICF/MR homes where residents are thriving despite their multiple severe disabilities.

3. FALSE: Intermediate Care Facilities for Persons with Mental Retardation (ICFs/MR) programs/services are "segregated", "confined" and "isolated".

RESPONSE: ICF/MR homes are specialized, Medicaid-certified programs which have proven to be key to the health and safety of those with the most severe disabilities. These homes are not segregated: residents have rich interactions with staff, families, their peers, and volunteers. These homes are not isolated: residents interact with a variety of persons during off campus employment and recreation opportunities. These homes are not confined: for many severely disabled persons, ICF/MR homes offer far more freedom on spacious, safe campus grounds than they would have in arbitrarily separated community houses or apartments.

4. FALSE: Institutional staff are only interested in saving their jobs.

RESPONSE: Well trained ICF/MR career staff render dedicated, competent and compassionate care.

5. FALSE: The ICF/MR model of congregate care is inhumane.

RESPONSE: Our experiences with ICF/MR programs are positive. We rely on the many eyes watching our family members who characteristically can express their hurts and needs only with great difficulty or not at all. The annual required reviews by the Office of Long Term Care are critical to health and safety.

6. FALSE: ICF/MR residents' civil rights are violated because they live in a segregated, congregate environment.

RESPONSE: An ICF/MR environment upholds and supports residents' civil rights by providing a safe, healthy, supportive home, carefully chosen by dedicated family members and/or legal guardians.

7. FALSE: States should eliminate the Medicaid bias by downsizing and closing ICF/MR homes.

RESPONSE: States spend far more on home and community based programs for people with developmental disabilities than for institutional programs. There is no Medicaid bias. The real bias is towards eliminating ICF/MR homes.

8. MISLEADING: Persons with the most significant disabilities can, with support, have meaningful employment.

RESPONSE: Persons with significant physical disabilities may be able to have supported, meaningful employment. Persons who are also severely cognitively impaired, functioning at a toddler's level, cannot be expected to have a job.

9. MISLEADING: Persons will thrive and be fully included in the community if they transition to smaller (less than 3 beds) community programs.

RESPONSE: It is well documented that persons with the most severe forms of cognitive/developmental disabilities who have transitioned from safe ICF/MR homes have been subject to horrific incidents of abuse neglect and exploitation.

10. MISLEADING: The medical term "mental retardation" is discriminating and hurtful terminology and must be changed to "intellectual disability".

RESPONSE: The reality is that "intellectual disability" is inexact and does not describe those with severe cognitive impairments. Our family members deserve a specific, accurate descriptive diagnosis.



NATIONWIDE SAFETY CRISIS IN SOME COMMUNITY PLACEMENTS

Senator Urges Federal Probe Into Abuse, Neglect Of Developmentally Disabled

By MATTHEW KAUFFMAN, JOSH KOVNER and DAVE ALTIMARI, mkauffman@courant.com

The Hartford Courant

6:47 PM EST, March 4, 2013

U.S. Sen. Chris Murphy is calling for a nationwide investigation into the "alarming number of deaths and cases of abuse" of developmentally disabled individuals at government-financed residential facilities.

Murphy sent a letter to the inspector general of the Department of Health and Human Services Monday, requesting an immediate investigation, with an emphasis on preventable deaths at privately run group homes.

"Privatization of care may mean lower costs but without the proper oversight and requirements for well-trained staff," Murphy wrote to Inspector General Daniel R. Levinson. "While individuals with developmental disabilities may not be able to speak for themselves, we are not absolved of the responsibility to care for them in a humane and fair manner."

Murphy was responding to stories in The Courant reporting on abuse and neglect of developmentally disabled residents in Connecticut group homes, state-run institutions, nursing homes and hospitals.

The series revealed that state investigators cited neglect in the deaths of 76 adults with developmental disabilities who were receiving services from the state Department of Developmental Services. One was placed in a scalding hot bathtub. Several choked to death despite protocols designed to address swallowing issues. A number showed signs of medical distress but received inadequate intervention.

Murphy said similar stories have appeared in newspapers in Virginia, New York, Massachusetts, Louisiana and Texas.

"There's clearly a volume of evidence — of journalistic evidence — over the last couple of years that this is a serious problem," Murphy said Monday. "So we're going to see if we can get a federal review here."

As a state senator, Murphy secured a moratorium on the privatization of group homes for the developmentally disabled. Since the moratorium expired in 2009, Murphy said, about 50 state-run homes have been converted to privately run homes.

Most of the deaths reported by The Courant involved residents of privately run facilities, but that is also where most of those in the system live. Murphy said the investigation he is seeking is not limited to private facilities, but said he is concerned that standards have slipped as private providers have become more common.

"I have always thought that we were privatizing too fast and that we didn't have enough concern for how to provide oversight over those private providers," Murphy said.

State officials have generally praised private providers, while also acknowledging the pressures of shrinking budgets and low wages for care workers.

The inspector general's office is not required to launch an investigation, but Murphy said he hopes his position on the Senate Committee on Health, Education, Labor and Pensions, which oversees the Department of Health and Human Services, will increase the likelihood that the office will agree to his request.

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SHELTERED WORKSHOPS SUPPORTED BY MISSOURI ASSOCIATION FOR PERSONS WITH INTELLECTUAL DISABILITIES (MO/AID)

The Department of Justice (DOJ) has taken a stand against sheltered workshops! The DOJ position is that limiting people with disabilities to employment in sheltered workshops is no different than restricting them to live in institutions.

The following is information in support of Sheltered Workshops from the organization Missouri Association of Persons with Intellectual Disabilities (MO AID) formerly Missouri Retarded Citizens (MRC). PO Box 831 Cape Girardeau, MO 63702-0831 (573) 334-1166 Their website is www.missouriaid.org.

“People with intellectual or developmental disabilities (I/DD), which includes mental retardation, Down syndrome, and cerebral palsy, have the right to choose where they work and where they live. We believe that sheltered workshops are the only places where some individuals can work and function as productive members of the community.

Legislators in some states are attempting to eliminate sheltered workshops and force people with disabilities into supported/competitive employment. A vast number of individuals with I/DD who are capable of supported employment have already transitioned into the community. There are countless horror stories about individuals who have tried supported employment, and they fell in with the wrong group of individuals, were taken advantage of, sent to prison, or ended up walking the streets alone.

Sheltered workshops provide a safe environment for adults with I/DD to work, interact with their peers, and gain a sense of accomplishment. Other popular names for sheltered workshops include “community rehabilitation programs,” work activity centers,” or “vocational workshops.” Many workshops also provide transportation, off-site day habilitation programs, and opportunities to experience new things such as taking a vacation or going on a camping trip. Individuals who choose to work in sheltered workshops are happy, safe, fulfilled, and are among their friends and peers.

The ARC of the United States claims that people with disabilities “have had no choice but to work in sheltered, segregated programs that separate people from their communities.” Our response is that supported/competitive employment has been a choice for more than 20 years, through the Division of Vocational Rehabilitation, Department of Mental Health, and the Medicaid system. Statistics show many individuals with I/DD have not shown an interest in supported/competitive employment, and the majority who have tried it, ultimately return to sheltered employment.

Some legislators claim that supported/competitive employment enables people with disabilities to live and work independently in the community. Our response is that it can *potentially* promote independence. In many cases, the individual ends up leaving a 29-hour a week job in a sheltered workshop for one where the individual only works one or two days a week for four hours a day. Working eight hours a week washing dishes alone in a restaurant kitchen is hardly integration into the community; however, current government standards accept this as a successful placement.

An alternative option, which is currently gaining ground, is to remove individuals with I/DD from sheltered workshops and place them in Day Habilitation programs – *segregated* programs where they receive no monetary wages! Each individual has an innate right to have the opportunity to work, earn money, and gain a sense of accomplishment and dignity, while contributing toward their own standard of living. Eliminating sheltered workshops as an employment choice, denies individuals with I/DD the human inalienable right to be a productive member of our society.

Community employment is not the answer for everyone. We need sheltered workshops! We should be creating more employment opportunities for people with disabilities – not eliminating options. ADA and Section 504 in no way meant to take choice or any other kind of employment option away from persons with I/DD. It is our responsibility to provide opportunities and support for individuals with developmental disabilities. Do not deprive them of their choices and force them into settings which will diminish their quality of life.

TAKE ACTION: Go to their website and sign a petition:
<http://www.change.org/petitions/protect-sheltered-workshops#>



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 "Bellevue Habilitation Parents Association"

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

THE HIDDEN TREASURE SHOP
SHOP TILL YOU DROP!! BEST THRIFT SHOP PRICES!!
NOW IN BLDG #1901 FIRST BUILDING ON THE LEFT AS YOU ENTER BHC CAMPUS.



WEDNESDAYS, 9 A.M. TO 3 P.M. AT BHC
Please leave donated items at the Parents Association shed near the Thrift Shop.



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BELLEFONTAINE HABILITATION CENTER
10695 BELLEFONTAINE ROAD
ST. LOUIS MO 63137

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