

President's Message

Dear VOR Friends and Family,

As VOR's outgoing president, I'd like to sum up my thoughts on where we have been and where we need to go at this critical juncture.

First, let's go back and look at where we've been. For several decades, we've fought a challenging battle to keep Intermediate Care Facilities – ICFs – from being closed. We've help to spare some while we have, regrettably, seen others shuttered. While this is not the sum total of all we've done, it has been our major focus, and for good reason: ICFs are the both the cornerstone of high-quality care and human rights for many of our loved ones, to which our advocacy is committed. Preserving the ICF system is the textbook example of whether individuals' and families' choice of what is best for our loved ones is to be realized. We need to learn from that history.

Now, let's take a look at the present. How do we best protect our loved ones' well-being, given our resources and abilities, amid the currents driving our society and the power of other influencers over disability policies at all levels of government? We must take account of the new Administration and Congress in light of how the courts, legislatures and federal agencies have interpreted *Olmstead* over a generation. Then, we must honestly assess what we ought to do, what courses of action are available to us, and work together to give it our best shot.

My conclusion is that, to contend with current realities, we need to hone our communication/advocacy tools more precisely to convey a rational, non-adversarial message linked to our policy proposals – which I believe we are now doing – and cultivate closer working relationships with our allies as a matter of mutual survival.

In line with this thinking, which is hardly only my own, we've nearly finished our first virtual Legislative Initiative, and will soon hold our first virtual Annual Members' Meeting, at which we will certify the results of our recent Board elections, , present reports from four of our core committees, and update members on our progress since last we met in 2019. Members will be given time to deliver reports on the state of I/DD services, policies and legislation in their States. Our guest speakers this year will be a representative from Health Policy Source and some key members of the Louisiana Dental Task Force, whose determination to provide quality dental care to the I/DD population in Louisiana is about to be signed into law.

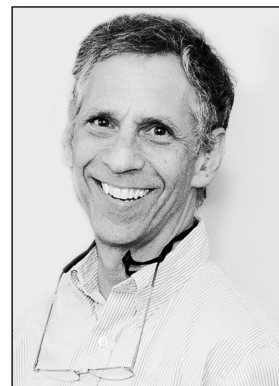
I hope to see many of you at the June 27th meeting.

It has been an honor to serve as VOR's president.

Sam Friedman

Sam Friedman

President, VOR Board of Directors



VOR's 2021 Annual Meeting

VOR's 2021 Annual Meeting will take place on Sunday, June 27th via Zoom at 3 pm Eastern, 2 pm Central, 1 pm Mountain, Noon Pacific. There is no fee for attending the conference, but we ask that you register online to ensure a seat in the meeting.

Please register online at www.vor.net

The Conference program will include:

- Address to Members from VOR's President
- Report on VOR's 2021 Legislative Initiative
- Reports from VOR's Finance, Legislative, Issues/Oversight and Quality of Care in the Community Committees
- Certification of the Election of Directors
- Ratification of Change to Constitution
- Guest Speaker - Mary Kay Cowen and members of the Louisiana Dental Task Force
- Introduction to Health Policy Source
- Reports from the States
- VOR's Annual Voice Awards

My Special Children - By Jeanette Craig



Bill and Jeannette at Bellefontaine Habilitation Center, St. Louis, MO. Christmas 2019

This is my story of my Special children. I married young and had 3 children by age 24. My 1st child was born in 1962, a baby girl with big blue eyes. We named her "Christine". She was the most beautiful child I have ever seen. When Chris was 16 months old, her sister, Kathy, was born.

Kathy had many problems. Her head and brain were malformed, and we were told she would never walk or talk and would only live 10 to 12 years. We were advised to place her in a home and "forget about her". I was incensed with that 'advice' and we took her home. She thrived, learned to talk (boy, did she ever talk), enjoyed reading, and telling jokes. She eventually learned to walk with braces, and was a very happy, delightful person who made friends with everyone. Unfortunately, Kathy passed away when she was 38 years old.

Our son, Bill, was born in 1964. He seemed to be a perfect baby with no obvious problems. He did have temper tantrums at a very young age, but we thought he would outgrow it. Our first sign that there was something wrong was that his speech was echolalic. That lasted only a few months, then he stopped speaking entirely.

We then made the rounds of Specialists.

My husband traveled, so care of the kids was up to me. I would take Bill on the bus to the Barnes Clinic for evaluations, testing, and blood draws. No one could come up with answers. Bill's behavior became worse, and I feared he would injure Kathy, as she was unable to defend herself.

Bill attacked Chris, me, and his father, often severely biting and causing injury. These attacks seemed to replace the earlier temper tantrums. We tried a privately run preschool for children with special needs. The Special School District was in its infancy and there was little help for families like us. Kathy did not qualify for SSD until she was 12 years old, and I finally got her toilet trained. Bill was able to go when he turned 6 years. It helped a lot until he got older and his behavior and attacks became quite violent. As he grew, I was not able to safely protect Kathy, as I was not strong enough. Therefore, we made the heart-wrenching decision to place Bill in a home. We chose a private setting that was fairly close to where we lived, as I thought this would allow me to visit him as often as I could and make it easier for him.

It was not a good place.

There was no privacy for the residents. There were two dorm-like buildings on the property, one for females, one for males. One time I went to visit and the boys were getting a shower. They were lined up, nude, in the shower room, had been soaped and, when I arrived, were being rinsed off with a hose. Bill lived there for about a year when the place was closed down by the State, and Bill was transferred to Bellefontaine Habilitation Center.

What a difference.

He has his own room that he sometimes shares with a compatible roommate. He has chores like he had when he lived at home with us. His father now lives in Florida, but we both participate in his care plan. We can visit Bill as often as we want.

Bill was about 12 years old when he moved to BHC. He is now 56. It is his home. He is happy there. He is frequently found on the front porch of his home, on nice days, on the porch glider. He is always glad to see me when I visit and walks me to the building with the soda machines because he knows there is money in my purse to get him a soda. He is still non-verbal, but has no problem making his wishes known by hand gestures, pointing, etc. As he has aged, his behavior has become much calmer, and though he still can get pretty upset at times, he does not seem to take it out on his housemates or me. The staff in his home care about Bill and the other residents.

I have not visited since the COVID restrictions because Bill would not understand why I can't hug him or give him a back rub (which he loves), or why there is a partition between us.

The staff in Bill's home at BHC are very good with him. They know how to calm him, what his food preferences are, etc. One of the staff allowed me to come to his own private home to drop off things for Bill that I want him to have.

That, I think, is above and beyond, and shows how much they care about the residents.

Bellefontaine Habilitation Center has been around as long as it has because of the staff and the care they give the residents. I feel it is the best place for my son, and I am so grateful for the care he gets there.

- Jeanette Craig, Mother of Bill Brueggemann

VOR is a 501(c)(3) non-profit organization. All donations to VOR are tax deductible to the full extent of the law. Please consult with your tax professional on how best to file your deductions.

Executive Director's Message - Part 1

have been difficult for many of us, for so many reasons, but things are beginning to return to normal. The COVID pandemic appears to be receding, dark clouds have been lifted, and we are again able to focus on our mission of supporting high-quality care and human rights for all people with Intellectual and Developmental Disabilities. Not only have we resumed our Annual Legislative Initiative and our Annual Members' Meeting (in somewhat different forms this year), but we have also engaged the services of a consulting firm in D.C., Health Policy Source, to amp up our advocacy work. To top it off, we have incredible news from Louisiana, where our long-serving Board member Mary Kay Cowen has shown how a simple conversation can result in complex legislation helping adults with I/DD to access quality dental care. Info on Health Policy source is on the next page, followed by documents from the Legislative Initiative, and then word about the accomplishments of the Louisiana Task force.



VOR's 2021 Legislative Initiative

VOR's 2021 Legislative Initiative was different from any previous year. For one thing, it wasn't held in Washington, D.C. Due to the ongoing COVID pandemic and the fact that many legislative aides are still working from home, we conducted our Legislative Briefings online via Zoom and our participants arranged virtual meetings or held conference calls with congressional staff and, in a few cases, even spoke with members of congress themselves.

Conducting the Initiative in this manner was a challenging endeavor for most of us. We've grown accustomed to setting aside a few days to advocate in D.C., burning up shoe leather running frantically across Capitol Hill for numerous in-person half-hour meetings with staffers. This year, the meetings have been spread out over a few weeks, and conducted from the comfort of our homes. But virtual meetings, though valuable, aren't as communicative as face-to-face meetings. It's difficult to make eye contact, and there is less back-and-forth discussion in meetings where participants are on "mute". Telephone meetings can be even more difficult. At times you get no reaction at all from the people on the other end of the line, but you just have to keep talking, stopping from time to time to ask if anyone has any questions or to otherwise engage the staffers.

Nonetheless, we all persevered, and the initiative has been far more successful than we dared hope.

Our requests this year were for CHOICE and PARITY. We asked congress to preserve a wide range of residential and employment options, and to provide funding for them all with equanimity. We asked congress to fund individuals, and their needs, rather than showing preference for any one ideology or funding stream over any other.

We chose to discuss three seemingly separate issues coming before members of congress, and show how when viewed together they illustrate a disturbing trend to overlook and marginalize more severely disabled individuals and the programs that cater to their needs in favor of programs that cater to socialization and inclusion for people with mild or moderate levels of I/DD and autism.

The HCBS Access Act of 2021 has yet to be introduced in Congress, but a draft of the bill was presented for comments a few months ago. It appears to have everything that mainstream "everybody does better in the community" advocates have ever wished for, including a subtext that would eliminate ICFs by providing full federal funding for only HCBS services. The bill would throw \$400 billion to HCBS settings, but fails to explain how it would solve the problem of a shortage of Direct Support Professionals (DSPs). You can build all the group homes you want, but they're no good to anyone if you can't staff them. The second issue, the American Jobs plan, has not yet been introduced either. It does propose to address the DSP crisis, but again, it would most likely only raise wages for DSPs in HCBS settings. Furthermore, if the bill is not passed, or watered down to exclude the DSP workforce, the HCBS Access Act would just throw money to HCBS providers without fixing the broken system. The third issue covers the "phasing out" (*i.e. elimination*) of Vocational Centers (sheltered workshops) and the 14(c) wage certificates that offer employment opportunities to a niche population of people with I/DD and autism who wish to work and develop skills in a non-competitive, therapeutic environment.

The documents we submitted to congressional offices appear on the next five pages, followed by a copy of "*Olmstead - Essential Passages Protecting Choice*" that many of us included in our follow-up emails. All of these documents are available for download on our website, at www.vor.net. We encourage our members to view them, download them, and share them with your state and local officials, or with your members of Congress when they come back to their state offices in August.

<https://www.vor.net/news-and-events/item/vor-2021-virtual-legislative-initiative>

On behalf of the members of the VOR's Board of Directors, our Legislative Committee, our Issues Oversight Committee, and our Quality of Care in the Community Committee, I would like to thank all of those who participated in this year's Initiative. Our work goes on. We remain hopeful and steadfast in our mission. And our "Voices Of Reason" continue to speak out on Capitol Hill.

Who We Are and Our Concerns for the 117th Congress

VOR – A Voice Of Reason - is a national non-profit organization that was founded in 1983. We advocate for high quality care and human rights for all people with intellectual and developmental disabilities (I/DD). We believe that choice among the widest possible range of options is the best way to meet the diverse needs of each member of the I/DD population.

VOR primarily represents individuals with the most severe degrees of I/DD and autism, and their families and guardians. Many of these individuals reside in federally licensed facilities where they benefit from a full range of services and 24-hour-around-the-clock support to meet their considerable needs. Thus, we work to support a full range of quality residential options and services, including own home, family home, community-based service options and Medicaid-licensed intermediate care facilities for individuals with intellectual disabilities (ICFs or ICFs/IID).

The I/DD population covers an extremely diverse range of individuals, each with their own unique abilities, disabilities, needs, and aspirations. Many individuals with I/DD can, with some assistance, make their own choices and work regular jobs. At the other end of the spectrum are individuals who function at the lowest level of these disabilities. They are full grown individuals age-wise who typically function at an intellectual level ranging from three or four months to two or three years. Most also have significant complicating physical and/or psychiatric/behavioral issues. They need assistance in feeding, bathing, toileting and diapering, dressing, lifting and the administration of medications and therapies. They depend on staff to attend to seizures, fit orthotic equipment to prevent deformities, address maladaptive behaviors and monitor the environment to prevent them from harming themselves or others, or to protect them from those who would do them harm. Many require special diets or must have their food ground or pureed in order not to choke.

The Biden Administration and the 117th Congress are embarking on ambitious plans to make long overdue changes to the systems that administer residential services and employment opportunities to people with I/DD and autism. We look on this with both hope and trepidation.

Over the last few decades, other advocacy organizations have worked to reduce the availability of the ICF option, arguing that ICF care violates individual rights, that everyone belongs in the community, and that integration into the society of non-disabled people is beneficial to all. This view denies the reality that for some individuals, their medical, behavioral and psychiatric needs are paramount to their well-being, not their degree of socialization with non-disabled individuals.

We seek a system that focuses on the individual, not on ideology. It is time to end the them-or-us, HCBS versus ICF, environment that forces individuals and families to make compromised choices. The best way to strengthen the system of supports for all people with I/DD and autism is to fund all options and let the individuals with I/DD and their families or guardians decide what is best for each individual.

The HCBS Access Act of 2021

Representative Debbie Dingell (D-MI), Senators Bob Casey (D-PA), Maggie Hassan (D-NH), Sherrod Brown (D-OH) and Tim Scott (R-SC) are in the process of drafting a bill designed to end waiting lists for people seeking Home and Community Based Services (HCBS) services. It would accomplish its purpose by providing 100 percent FMAP (federal funding) for HCBS services and supports. VOR has submitted comments to the committee drafting this bill,¹ and now we would like to share our concerns with your office.

While the draft bill would help get people off the waiting lists, it would do so at the expense of the more than 67,000 people who, due to numerous medical, psychiatric, and behavioral needs, receive life-sustaining services in Intermediate Care Facilities for Individuals with Intellectual and Developmental Disabilities (ICFs/IID or ICFs). The reason is simple. Because the bill would provide 100 percent federal funding for HCBS services while maintaining a federal-state cost sharing arrangement for ICFs, the states would have an overwhelming financial incentive to discontinue the ICF program. They would simply close their ICFs and transfer the residents to HCBS settings. The problem with that approach is that the ICFs provide almost exclusively for those with the most severe and profound levels of intellectual disability and coexisting medical and behavioral challenges.

The private sector proponents of the draft bill contend that “everyone does better in community settings” *i.e.*, small group homes. Our members’ experience has too often been to the contrary, finding that group homes lack the comprehensive medical and other care their severely disabled loved ones need. The proponents also insist there is an “institutional bias” in the system that delivers services for people with I/DD that favors ICFs. In fact, 50 states have ICFs while 47 have HCBS. The federal government spends about five times as much on HCBS waiver programs as on ICFs. In FY2018, nationwide Medicaid spending the HCBS waiver program was \$35 billion versus \$7 billion for ICFs/IID.

VOR asks that Congress take this opportunity to abandon the “us-versus-them” atmosphere in the disability community over where people receive services. There should only be “us”, and the system that administers services should provide for everyone according to their **individual needs** and **individual choice**. If Congress decides to increase the federal share of services for people with I/DD, it should apply equally to all service options.

¹ <https://www.vor.net/legislative-voice/item/vor-comments-on-proposed-hcbs-access-act-of-2021>

The American Jobs Plan

President Biden has outlined a major infrastructure policy initiative that the Congress will be considering in the months ahead. While the details have not been filled in yet, the White House fact sheet for the plan says it will address the “infrastructure of our care economy by creating jobs and raising wages and benefits for essential home care workers.” It also calls for providing home and community-based care for individuals on the waiting lists. As this legislation will affect the lives of our family members with I/DD and the Direct Support Professionals (DSPs) who attend to their daily and long-term care, we encourage President Biden and the Congress to consider our concerns about protecting individuals with the most severe disabilities as you craft legislation.

The plan envisions making significant changes in the structure of the DSP workforce. Today’s DSPs too often face minimum wage salaries and receive little recognition for their important work. As a result, they are undertrained, must work multiple jobs to make ends meet and move on to higher paying fields frequently. The system is harmful for the residents who need quality care. We hope the plan will provide DSPs with salaries and benefits commensurate with those received by other health care professionals, and that it will contain provisions for education and training to encourage workers to look upon this position as a career.

Unfortunately, the plan as described would divide developmental care services into two silos, one for HCBS’s and one for ICFs, and provide funding only for the former. It would add \$400 billion in federal funds for HCBS services only. Some advocates for this position argue that this approach is needed to overcome an institutional bias, i.e., that the ICF program is mandatory while the HCBS program is optional. It is a distinction without a difference. Fifty states have ICFs while 47 have HCBS’s. Advocates who favor more funds for the HCBS program alone ignore the fact that the federal government spends about five times as much on HCBS waiver programs as on ICFs. More importantly, the same workforce works in ICFs as in HCBS group homes and each need higher salaries, better education and a career path.

We ask simply that this initiative be about the individuals with special needs and the people who provide care. It should not choose one form of care over another. The form of care should be determined by the needs of the individual and their choice among the widest possible range of services available to meet their needs and desires, not by the ideology of some. We ask that the \$400 billion in federal fund include comparable funding for ICF services and employees as well as for HCBS

Please Oppose Elimination of Section 14(c) Subminimum Wage Certificate Program that Provides for Vocational Centers for Individuals with Intellectual and Developmental Disabilities

Just as your neighbors and friends vary in ability, so do people in the disability community. VOR believes the best way to address individual needs is by providing the widest possible range of options and letting the individuals with intellectual and developmental disabilities (I/DD) or their families or guardians decide what fits the individual best, be it in choosing residential or employment options. We are concerned that several bills that seek to expand work options for some in the disability community would deprive the severely disabled people we represent of work opportunities. We believe the legislation can be modified to address both concerns.

Section 14(c) of the Fair Labor Standards Act authorizes the issuance of specialized wage certificates that permit employers to pay individuals with I/DD lower than the federal minimum wage when their level of productivity is so low as to make them noncompetitive in the general workforce. It requires employers to make special accommodations for their intellectual, physical, behavioral, and mental illness challenges, giving thousands of individuals with I/DD the opportunity to work in a specialized environment that nurtures them and fits their abilities. They earn wages that are appropriate to their level of productivity and their capacity to work. Without 14(c) certificates, these individuals would lose any opportunity to work.

Employment usually takes place at facility-based work centers, formerly called “sheltered workshops”. These vocational centers provide a specialized environment adapted to individuals with I/DD who desire to work, but may have frequent seizures, act out physically, even violently, when stressed, or need help toileting or having their adult diapers changed.

At the centers, workers crush cans, fold letters and stuff envelopes, fill soda bottles, and perform many small-piece assembly tasks. Each employee has a job coach (direct support professional). Sometimes they work alone and sometimes they perform these tasks with assistance. If the centers had to pay them minimum wage, they would have to close, leaving the workers unemployed.

The **Raise the Wage Act of 2021**, (*H.R. 603 and S. 53*) includes provisions to raise the minimum wage to \$15 per hour for all workers, including individuals with I/DD. This legislation would phase out the section 14(c) certificates. Additionally, the **Transformation to Competitive Integrated Employment Act** (*H.R. 2373*) contains support for the phase out of Section 14(c) certificates and schedules annual increases in the minimum wage that existing vocational centers must pay workers over the next six years, effectively forcing them out of business. These bills would completely eliminate employment opportunities for thousands of the nation’s most disabled individuals.

The centers provide more than employment. They afford workers opportunities to build self-esteem, develop friendships, and engage in their communities. People who work at these centers do so without fear of being fired, or of having to live up to competitive standards of productivity in order to show their worth. Earned wages, though appreciated, are not the substantive reward for these individuals.

The answer is simple: provide opportunities for competitive employment for people with I/DD who can, with reasonable accommodations, perform at a competitive level of productivity, and support vocational centers and Section 14(c) programs for those who cannot.

Myths and Facts about Vocational Centers for People with I/DD

MYTH: People with intellectual and developmental disabilities (I/DD) and their families are dissatisfied with vocational work centers.

FACT: Vocational work centers (also known as sheltered workshops) are valued for the services they provide to people with I/DD who are unable to adapt to competitive employment. When these centers are threatened with closure, employees with I/DD and their families are the most fervent advocates for keeping them open.

MYTH: Vocational work centers are isolating environments.

FACT: These work centers are part of the greater community. Those who choose jobs at work centers develop a sense of accomplishment and self-worth because of work completed. Far from being isolating, they offer people a sense of camaraderie and a chance to interact with their peers.

MYTH: Vocational work centers are the only choice for work for people with intellectual disabilities.

FACT: There are many resources available through state vocational rehabilitation departments to assist with opportunities for competitive employment. No one can legally be forced to work in a vocational work center.

MYTH: Work centers do not provide opportunities to transition to competitive employment in the community.

FACT: For those who can develop skills to work in competitive employment, work centers provide opportunities to learn skills necessary to be successful such as being on time, working with others, and completing assigned tasks.

MYTH: All people, no matter the nature of their disability, can find competitive employment.

FACT: Some individuals have more difficulty adapting to competitive employment. Vocational centers provide opportunities for work while providing more specialized supports such as personal hygiene care, preventing and attending to seizures, or helping with behavioral issues and developing social skills.

MYTH: Work centers do not provide for meaningful jobs.

FACT: Examples of work opportunities include: manufacturing, item assembly, recycling, packaging, repair, and machine operating. <https://dese.mo.gov/special-education/sheltered-workshops/jobs-performed-sheltered-workshops>

MYTH: Oversight of vocational work centers is lax.

FACT: According to the Department of Labor: "All subminimum wages must be reviewed and adjusted, if appropriate, at periodic intervals. At a minimum, the productivity of hourly paid workers must be reevaluated every six months and a new prevailing wage survey must be conducted at least every twelve months."

<https://www.dol.gov/whd/regs/compliance/whdfs39.pdf>

MYTH: Vocational work centers violate the 1999 Supreme Court Olmstead decision.

FACT: The 1999 Supreme Court Olmstead decision supports CHOICE. Closing these centers contradicts the opinion expressed by the majority of Justices in Olmstead by eliminating a desired, chosen and helpful employment option.

MYTH: Eliminating 14(c) certificates of the Fair Labor Standards Act will increase employment rates of all individuals with disabilities.

FACT: 14(c) wage certificates of the Fair Labor Standards Act allow employers to afford to provide the specialized services needed by people with I/DD who are not able to adapt to competitive employment. Eliminating these wage certificates will force the closure of vocational work centers, eliminating jobs with no replacement in competitive employment.

In 2016, I had a conversation with Jane Anthony of Virginia about the need for VOR to reach out to families whose loved ones had moved out of ICFs and into the HCBS system. Jane’s son Jason’s state-operated ICF, the North Virginia Training Center, had been closed by the DOJ, and her family had chosen to move him to a nearby group home rather than an ICF at the other end of the state. A few weeks later, Brad Whitehead and I put together a new group, the Quality of Care in the Community Committee (Q of C) to address these issues. Brad had been a direct support professional in California, and saw the need arising as his state determined to close its thirteen centers.

One of the first issues we discussed in the Q of C was the need for dental care in community settings. Access to good dental care wasn’t an issue in most state-operated ICFs, but it was a major hurdle for families in group homes. Brad brought in Dr. Matt Holder of the Lee Specialty Clinic in KY, and VOR’s George Mavridis joined the committee to share his work with establishing training for dental students at Tufts University to learn how to better deal with the I/DD population. We spoke with people at CMS and the Administration for Community Living about this need, and offered ideas for how they might use their agencies’ political clout and finances to help fill the gap in services for people in community settings, and even spoke with people at the American Dental Association. Everyone we spoke to sounded interested, but nothing much came to fruition. Until now.

One member of the Q of C was Mary Kay Cowen, who serves as guardian for her brother Tommy. In 2012, she had moved Tommy out of a state-operated ICF and placed him into a smaller, private setting. Mary Kay was pleased with the services that her brother was receiving, except he wasn’t getting proper dental care. Inspired by our discussions in the Q of C meetings, she set out to do something about it. She kept speaking up at local and State-wide meetings until the Louisiana State Advisory Committee she was on created a Dental Task Force charged with coming up with a report to address the unmet dental health care needs of adults with I/DD who need anesthesia or IV sedation. Borrowing a few ideas from Matt Holder’s presentations, obtaining input from Tufts University through George Mavridis’ connections, and with the help of her new friend Kathy Dwyer and others on the Dental Task Force, she wound up with an impressive group of advocates in the Baton Rouge/New Orleans area to define goals and determine policies they wanted to see put in place. Their primary goals included:

- 1) Provide comprehensive dental health coverage for adults similar to the coverage given to children to prevent more serious and costly medical issues.*
- 2) Develop pre-doctoral dental education programs as required by the Commission on Dental Accreditation (CODA) along with a post-doctoral training for CEUs to build and expand on the capacity and competency of the existing dental workforce in public and private practice.*
- 3) Make necessary dental equipment available in hospitals and outpatient surgery centers throughout the state so dentists have the equipment needed.*

Once the task force had completed its original goal of creating a report, no one in the committee wanted to stop the forward momentum of making something happen. With the approval of all involved government entities, they sent their report to legislators who were known to have an I/DD family member and found State Representative Rhonda Butler who was determined to enact legislation guaranteeing the state would provide quality dental care to people with I/DD. A bill has passed the state house assembly and senate with unanimous support and now awaits the Governor’s signature providing care for adults in Louisiana’s DD Waiver Programs. Because ICFs are funded differently, Rep. Butler presented a House Resolution which also passed unanimously mandating Louisiana Department of Health come up with a way to implement the same program for people in private ICFs and group homes.

We hope that Mary Kay’s work in Louisiana will inspire other members of VOR to enact similar bills in their states, or encourage others to bring the issues that most affect their loved ones to their state capitols and find elected officials who are willing to act on behalf of people with I/DD.



Rep. Rhonda Butler, Mary Kay Cowen, Kathy Dwyer & her daughter Jennifer Blanque



VOR is pleased to announce that we have engaged the services of Health Policy Source

HPS is a consulting and lobbying firm based in Washington, D.C. HPS offers expertise in healthcare policies and legislation with high-level, political strategy and advocacy services.

HPS was founded by Dan Boston, who has been named one of Top Lobbyists for 2020 by The Hill, a Washington, D.C. newspaper. Dan has received this honor an unprecedented 17 of the last 18 years. Before entering the private sector, Mr. Boston served in a number of key positions on Capitol Hill, most notably as a member of the Majority Staff of the House Committee on Commerce's Health Policy Team, Communications Director & Policy Advisor to Congresswoman Sue Kelly (R-NY), Press Secretary to Congressman Joe Knollenberg (R-MI), and press and political aide to Senate Republican Leader Mitch McConnell (R-KY).

In addition to Mr. Boston, VOR will be working with Gayle Gerdes and Keith Snider. Ms. Gerdes's health care background comprises an extensive mix of government and private sector experience. She spent several years on Capitol Hill where she worked in both the House and the Senate focusing on health care legislation. Later she moved to The Concord Coalition where she worked with the media, Members of Congress, and related organizations to educate the public on the federal budget and deficit.

Keith Snider is HPS' Health Policy Director. He provides client management and policy support on a variety of issues in the Medicare and Medicaid programs. In this position, Mr. Snider concentrates on monitoring legislative and regulatory activity, crafting policy memorandums and issue briefs, and providing legislative and regulatory analysis. Prior to joining HPS, Mr. Snider spent five years as a journalist with Bloomberg News in Washington, D.C., where he covered the hospital, managed care, and medical device industries, as well as Medicare payment issues and the emergence of concern over healthcare cost increases.

Craig O'Connor and His Home, Southbury Training School (STS)

My name is Kyrie and my brother Craig O'Connor has called Southbury Training School home since the early 60's. I am Craig's sister and guardian.

STS is a state-operated Intermediate Care Facility (ICF). It was built in the 1930's on a beautiful 1,600-acre campus in Southeastern Connecticut as a state-funded, state-operated residential and habilitative facility for adults with intellectual and developmental disabilities (I/DD).

My parents moved to Connecticut to get him into the training school. It was their wish that he stay at STS for the rest of his life. Craig is severely disabled, having suffered oxygen deprivation at birth. He cannot walk by himself-he is wheelchair bound, he needs help dressing, using the bathroom and grooming. He has severe mood swings and can be violent. He is on a number of medications to keep mood positive. Overall, Craig could not survive if he was not in an ICF.

We will celebrate a milestone in Craig's life, as he will be turning 70 in June. I credit the loving and caring staff at STS for his remarkable good health and humor. Keeping him happy and healthy has been very challenging. This is a difficult task for anyone as you need to understand his frame of mind and tend to his extensive physical needs. The staff are extremely attentive and lovingly care and protect Craig, even from himself when he is self-abusive during emotional distress. They have known him for years, and over that time, some of them have been able to make a strong personal connection with him. His day program has been especially positive for Craig, he has enjoyed his trips to and from the facility and having his abilities increased in the training center.



During our quarterly meetings, the staff are always thinking about how they can do their job better when it comes to Craig. Overall, he is a happy chatty guy (even though I can't understand much of what he says). He loves his hats and his Fischer Price wind up radios almost as much as he enjoys eating. (I must have bought him a hundred of those radios!)

Craig's meals are ground up so he does not choke on the food, and his liquids have to be thickened, but he always has a robust appetite. The staff that have been with him for years, know that Craig has a "sweet tooth", yet they are very disciplined in his diet as he needs to maintain a certain weight to make sure he is healthy. Everything is documented and thoroughly discussed during every quarterly meeting. If there are any issues, I am immediately called, appraised of the situation and provided with any action that has been taken. Importantly, I know many of the staff consider "Craigie" or "Irish" as part of their extended family. Craig is fortunate to be in such good hands.

I love my brother and I do not worry about him because he is well taken care of at STS. My only worry is that STS may not always be there for Craig, or for others in his cottage, if the state ever moves to close the training school.

PRINCIPLES

Adults with I/DD have the right to a healthy life in order to be active and productive citizens in Louisiana and their community of choice.

Access to affordable dental health care is a critical component to maintaining overall health and economic security.

Adults with I/DD should be afforded preventive and restorative dental remedies so that they can retain their natural teeth, be free of infectious disease, be able to chew their food properly, and maintain proper nutrition.

* Healthy Louisiana Dental Plan Comparison Chart (July, 2020). https://www.myplan.healthy.la.gov/sites/default/files/Documents/LAEB_DentalCompChart_2020_ENG_WEB_101420.pdf

Louisiana Task Force for Dental Services Adults with Intellectual/Developmental Disabilities (December 11, 2020). Formal Report to the Louisiana Department of Health and Other Relevant Agencies. <https://drive.google.com/drive/folders/1ONQPIfeviJRC-uynpba7VjIG4HetbhJ?>

Louisiana Dental Task Force
for Adults with
Developmental Disabilities

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Comprehensive Dental Services for Adults with Developmental Disabilities

March 26, 2021

What We Need Legislators to Do?

Provide Comprehensive Dental Services through Louisiana's Developmental Disabilities Waiver Programs as well as an allocation to Intermediate Care Facilities for Developmental Disabilities (ICF/DD) so that adults with I/DD can receive the dental health care services they need to prevent negative outcomes for both medical and behavioral health as well as economic hardship experienced by adults with I/DD and their families in Louisiana.

Why We Need Legislators to Fund This?

Adults with I/DD have gone too long without the necessary and needed dental health care leading to fair to poor overall health/sometimes life-threatening health issues.

Studies have shown adults with I/DD are at risk for multiple health problems including poor oral health and are four times more likely to report their health to be only fair or poorer than people without disabilities.

Some adults with I/DD have aversions to probing in their mouths and need special accommodations to support their access to affordable dental health care.

Adults with I/DD who have aversions experience extraordinary costs just for a routine dental exam and cleaning which at minimum includes an outpatient surgery center or hospital stay with anesthesia, diagnostic tests, labs, etc.

Adults with I/DD have limited income because of their disability.

Traditional Medicaid offers only an Adult Denture Plan (ADP) for adults 21 y.o. and older and is limited to an exam, diagnostic radiograph, and preapproved dentures or partial and denture combination. Any necessary restorations, dental cleanings, and outpatient hospital stays requiring anesthesia are not covered. A set of dentures is limited to one set every 5 years for adults who are 18-20 yrs. old, and every 8 years for adults age 21 and older. However, individuals diagnosed with severe to profound I/DD typically do not tolerate the construction process nor are able to wear or maintain dentures. The Medicaid Managed Care Organization (MCO) plans are also limited in services, providers, and restrictive in eligibility or cost prohibitive for individuals with behavioral challenges and complex medical issues.*

Limited Medicaid coverage for dental health care leads to extraordinary and **unnecessary, overall medical costs** for the individual with I/DD, their families, and the State.

WHY ADULTS WITH DEVELOPMENTAL DISABILITIES SHOULD RECEIVE COMPREHENSIVE DENTAL CARE

ADULTS WITH DEVELOPMENTAL DISABILITIES EXPERIENCE



Greater unmet health care needs than the general population (1)



Unequal access to health care services (1)



Greater barriers to obtain education (1)



Lower employment rates (1)



Higher poverty rates (1)



The need for sensory and behavioral supports (1)

OVER-DEPENDENCE OF EMERGENCY DEPARTMENT (ED) ROOMS FOR ADDRESSING DENTAL NEEDS



On average, every 15 seconds, someone visited a hospital ED for dental conditions in 2016 (3).



2.2 million total number of hospital ED visits for dental conditions in 2016 (3).



\$2.7 billion dollars spent on hospital ED visits for dental conditions in 2017 (3).



25% of adults who were treated in hospital EDs returned within a year with a similar dental complaint (4).

Dental care is the #1 unmet health need among adults with developmental disabilities (2).

PREVENTION IS KEY

Studies have shown that for every dollar spent on preventive dental care – \$8 to \$50 can be saved in restorative and emergency treatments – and potentially more in additional types of medical treatment (5).



A reduction of 1% in all dental claims for ED users for dental condition could lead to a savings of \$6.1 million based on an average expense per ED user of \$637 per visit for non-traumatic dental conditions (6).



Those who practice good preventive oral health care can save 31% in dental costs over 5 years. Likewise, adults who don't receive preventive care can expect a 43% increase to their annual dental costs over the same period of time (4).



Adults with disabilities are 4x more likely to report their health to be only fair or poor than people without disabilities. More specifically, adults with developmental disabilities are at risk for multiple health problems including poor oral health (7).

Oral health is linked to overall health, disease in the mouth can spread to other parts of the body. Poor oral health is associated with other chronic conditions as well as increased behavioral issues including but not limited to (8,1):



Obesity



Elopement



High Blood Pressure



Aggression



Heart Disease



Depression



Alzheimer's Disease



Refusal to Eat

Diabetes

ACTIONS TO PROMOTE CHANGE

1

Provide comprehensive dental services, including anesthesia, for adults with intellectual/developmental disabilities in the Medicaid Home- and Community-Based Services Waiver Program and an allocation for Intermediate Care Facilities for Developmental Disabilities (ICF/DDs).

2

Provide enhanced pre- and post-doctoral special needs dentistry education program, including a parent/family and behavioral health components at the LSU School of Dentistry to train dental students and the existing dental workforce in order to build capacity and competency in public and private practice.

3

Increase the number of hospitals and outpatient surgery centers available for dental procedures by making dental equipment available to dentists in area hospitals and outpatient surgery centers for use by public and private practitioners.

DENTAL CARE DISPARITIES COMPARISON

ROUTINE PREVENTIVE CARE

Adult with Intellectual/Developmental Disabilities

\$199.92-
\$272.92

Includes: Dental Exam, X-Ray and Cleaning with or without in-office sedation

General Adult Population

\$199.92

Includes: Dental Exam, X-Ray and Cleaning

Adults with Intellectual/Developmental Disabilities with Aversions

\$3,649.62

Includes Dental Exam, X-Ray and Cleaning and required (2015):

- General anesthesia (approx. 60 mins)
- Hospitalization
- Diagnostic tests and labs

General Adult Population

\$199.92

Includes: Dental Exam, X-Ray and Cleaning

Adults with Intellectual/Developmental Disabilities with Aversions WITHOUT COMPREHENSIVE COVERAGE OR DENTAL CARE

\$10,000 -
\$500,000

Includes: Multiple Emergency room visits, multiple Hospitalizations, Wound care for infections and abscess, Labs and x-rays, additional direct support worker hours, **urgent and more extensive dental care still needed.**

Adults with I/DD with Aversions WITH COMPREHENSIVE COVERAGE THROUGH MEDICAID WAIVER PROGRAM and ALLOCATION TO ICF/DDs

** Costs are a range from a sample of 10 claims.*

\$155.55

Preventive Care
WITHOUT Anesthesia

\$635.19 -
\$739.13

*Preventive Care **WITH**
Anesthesia

\$603.46 -
\$3,681.50

*Restorative Care
WITHOUT Anesthesia

\$1,097.94 -
\$4,205.68

*Restorative Care **WITH**
Anesthesia

PREVENTIVE CARE includes: Dental exam, x-rays, and cleaning as well as anesthesia, hospitalization, diagnostic tests, and labs when required.

RESTORATIVE CARE includes: Fillings, extractions, crowns, root canal, etc. as well as anesthesia, hospitalization, diagnostic tests, and labs when required.

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**A national, non-profit 501(c)(3) volunteer organization
speaking out for people with intellectual and developmental disabilities**



**VOR's Annual Meeting will be held on
June 27th, online via Zoom
Details inside**

Please note: Your membership expiration date is listed on the bottom of the address label above.

Membership / Contribution Form

Mail this form to: VOR, 836 S. Arlington Heights Rd. #351, Elk Grove Village, IL 60007

Fax to: 877-866-8377 or donate online @ <http://www.vor.net/get-involved>

Thank you for your dues and contributions!

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NAME _____

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ADDRESS _____

CITY _____ STATE _____ ZIP _____

CITY _____ STATE _____ ZIP _____

TELEPHONE _____ FAX _____

TELEPHONE _____ FAX _____

EMAIL _____

EMAIL _____

☐ **MY CONTACT INFORMATION HAS CHANGED**

☐ **\$45 per year per individual;**

☐ **\$200 per year per family organization**

☐ **\$250 per year per provider / professional org.**

☐ **I would like to make monthly donations to VOR. Please charge my credit card each month for: \$ _____**

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If the minimum dues requirement poses a financial difficulty, please contact our office in confidence (877-399-4867). It is in our best interest that you receive VOR's information. If you have included VOR in your estate planning, or establish a memorial fund, please contact us. If you would like additional information about your planned giving options, please call Hugo Dwyer at VOR, 646-387-2267 or hdwyer@vor.net.

June, 2021NL

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