



A Message From VOR's President and Executive Director

As the Summer fades to a memory, we are beginning the second and most challenging part of our year. Fall is here, bringing with it baseball playoffs, football, flannel, apple cider, leaf-watching, and the traditional VOR Fall and Winter Membership & Fundraising Campaigns. And yes, you will be hearing quite a lot from us over the next three months. The last few years have been incredibly challenging for non-profit organizations, and VOR is no exception.



For thirty-nine and a half years, VOR has had to balance our very important advocacy work, *speaking out for our family and friends with intellectual and developmental disabilities (I/DD) and autism*, with the need to raise the funds in order to sustain our organization, thereby allowing us to continue to advocate for choice in residential care and employment opportunities for people with I/DD and autism.

Over the past year and a half, VOR has kicked up our advocacy considerably. We have secured the expertise of health policy experts who have helped us to execute innovative advocacy strategies and provided introductions to key members of congress, which has enabled us to develop relationships and engage our VOR members in meetings and discussions. This has been critical in continuing our advocacy in the aftermath of the COVID pandemic and the postponement of our Annual Legislative Initiative in Washington, DC.

We have not lost a beat. In fact, the two of us have held more than 125 Zoom meetings with key members of the 117th Congress. We have helped VOR families across the country to hold dozens of virtual meetings with staff from their own members of the House and Senate. In addition, we have met with members of the Department of Justice (DOJ), Center for Medicare and Medicaid Services (CMS), Administration for Community Living (ACL), and the President's Committee for People with Intellectual Disabilities (PCPID), to provide testimony and discuss the issues that affect our families. We have advised on bills to protect Intermediate Care Facilities, to preserve 14(c) work opportunities for individuals with I/DD and autism, and to increase pay, training, and benefits for direct support professionals to alleviate the DSP crisis. We have collaborated with our allies in Together for Choice, the Coalition for the Preservation of Employment Choice, the National Council on Severe Autism, AFSCME, and the National Association for Rare Diseases to advance legislation promoting our mutual goals of improving the lives of our nation's most vulnerable citizens.

The thing is, we cannot continue this work without your financial support. Our family members with severe and profound intellectual disabilities and autism represent only about 5% of the entire population with I/DD. We must work very hard to be heard. If we do not speak up for them, who will? As you know, VOR is 100% privately funded through donations from members like you. Our mission can only be accomplished through volunteer efforts and the generous financial support of our members and friends. Every member is important, and every gift really does count. We are grateful to you for your years of support to VOR and ask that as you plan your year-end charitable giving, you would again please consider a gift to VOR.

Most Sincerely,

Joanne St. Amand
President, VOR Board of Directors

Hugo Dwyer
Executive Director, VOR – A Voice of Reason

Laura's Story – The Right to Work & Live with Support Systems

By Dawn Kovacovich

Board of Directors, Coalition for the Preservation of Employment Choice / Parent Advocate, A-Team, Minnesota

Our 31-year-old daughter, Laura, has a point of view that is often overlooked when policies and opinions are formed regarding integration and best practices for people with disabilities. She was born 3 months prematurely with multiple handicaps; including Autistic Spectrum Disorder, Obsessive Compulsive Disorder, and severe vision and hearing loss. She also has pervasive anxiety issues that can quickly and unexpectedly lead to violent outbursts.

Most of us perceive integration only from the perspective of what we want for ourselves. What we don't usually think about is what it might feel like to always be in the minority. Like most people, Laura has scattered abilities, so with 1:1 paraprofessional support, Laura was able to successfully attend public school in a "fully integrated" setting with nondisabled peers. At the time, my husband and I felt that this model would provide Laura with the best education possible. However, due to the severity of her anxiety and social limitations, this would not have been possible without having 1:1 paras. This model is extremely costly and typically not feasible. When we observed how Laura absolutely blossomed every year when she attended summer camp with other autistic children, in a setting that was structured to meet her individual needs and with staff and peers who understood and even celebrated her unique behaviors, we began to rethink what integration really means. From Laura's point of view, the "integration" the general public seems to want for her is to remain in the minority, rather than part of a majority of like-minded individuals.

This position was firmly recognized when Laura started working at the Hubbard County Developmental Achievement Center (DAC) and the Bearly Used Thrift Store in Park Rapids, MN. After graduating from High School, Laura was able to remain at her High School for one more year as a student worker. She loved her volunteer job in the office, sorting and delivering staff mail. It gave her a sense of purpose and she felt comfortable and happy. However, when she started working in Park Rapids a year later; for the first time in her life, Laura was able to work in a setting where her like-minded peer group was the majority and non-disabled people (her work supervisors) were the minority. She made close friends. She felt safe instead of vulnerable. She did not feel overwhelmed or pressured. When she needed help, it was immediately available. She was encouraged to try a variety of jobs, including rug making, filing, and pricing and shelving items. She chose the jobs she liked best and was regularly assessed for productivity at those jobs so that she would receive fair compensation, commensurate with prevailing minimum wage, for her work. There were developmentally appropriate events; exercise and creative opportunities; and parties that helped create a strong sense of community and belonging. Instead of coming home quiet and subdued, Laura literally bubbled over with how much "I love my jobs!!!" every day. She started playing games with peers and asking to go on outings with others, which was a particularly remarkable step for Laura. The DAC offers informed choices for day activities, competitive work in the community with job coaches, and employment in various supported DAC settings.



Laura loves riding horses. Here is a picture from a few years ago with her housemate LouAnn.

Laura feels very strongly that she should have the right to choose her own friends, have the right to work at her own pace and ability for pay, and live with other disabled individuals in a safe, fully staffed environment. Several nondisabled or mildly disabled lawmakers and advocates have claimed that it is "isolating" and "segregating" to allow handicapped people to live and work together. They have created laws that prevent licensing for Assisted Living facilities for the developmentally disabled (ICFs), lean toward laws that push for "fully integrated" competitive employment, and have frozen the funding for group homes. Without a center based, supported work setting, Laura would not be able to work at all. The discriminatory action of ending commensurate wage provisions (14c), eliminates the right for her to work. There are simply no appropriate settings and support systems in place in the competitive employment sector that could meet her needs, much less an environment where she could make real friends. Accommodated wages have allowed her to reach her full potential and to continue to grow as an employee, gradually developing work skills in jobs that make her happy and fit her abilities.



Laura loves her jobs. Here she is at her center's loom, where she developed her weaving skills.

After seven years of practice, Laura earns minimum wage working in the center-based program as a rug weaver, producing quality rugs at an average productivity rate, where she and works side-by-side with others who earn special wages. She loves the camaraderie in this work setting. She is also able to work for commensurate wages at a downtown thrift store that is owned and operated by the same nonprofit disability service provider. This job stretches her abilities and helps her continue to grow and learn, although she is far less productive than an average, nondisabled employee. Although this work setting is in the public, it is also staffed with fully trained supervisory staff and is tailored to meet the needs of its employees who have disabilities. It is simply not economically feasible for any type of business to provide support staff and pay full wages to disabled employees who are not able to work at an average capability.

Laura enjoys earning a paycheck at work because it makes her feel like a productive adult. She has very minimal understanding about finances, and the monetary value of her paycheck means very little to her. Due to the severity of her disabilities, Laura has qualified for funding that already provides for her living

expenses. Earning minimum wage is not important to her, but having a productive and meaningful job in a developmentally appropriate setting is EXTREMELY important. She knows that if the provisions of 14C (special minimum wages) are eliminated, her quality of life will change dramatically. We are all deeply concerned about how the loss of this right and her beloved routine will affect her anxiety and behavior.

Laura waited seven years on a waiting list for an opening at a group home in our local community. Unless a current resident moves or dies, there is no supported housing available that can meet the needs of a severely handicapped individual. Until then, Laura lived with us in rural northern Hubbard County. During that time, we drove 50 miles, twice a day, to meet the DAC bus so Laura could continue to work at the DAC instead of being isolated at home all day. When she was finally able to move into her new home, Laura truly felt like an independent adult. The house is fully staffed in order to provide necessary support, supervision, and transportation for its residents; but just like any other adult person, having the choice and resources available to live independently from one's parents is a right that Laura feels every handicapped person should be allowed. It was a huge and exciting step for her! She is part of the broader community now and has formed very close attachments to her housemates and caregivers.

Again, Laura feels very strongly that disabled people should have the right to choose their own living and working space. This includes the right to live in an Assisted Living (ICF) or Group Home Facility if that is the environment that best meets their needs. It also includes the right to choose to work with other disabled people in supported work settings or sheltered work centers for "sub-minimum" (commensurate) wages. This option will not prevent other disabled people from working in less supported settings if they have those capabilities, but will accommodate people who need this structure. She is extremely grateful to enjoy a wonderful quality of life at this time and hopes that people will continue to allow her these opportunities.



Laura with Rocky-the-One-Eyed-Horse. Rocky is blind in his left eye and Laura is blind in her right eye, so she says they are "a perfect match"!

In the recent drive toward "inclusion", many of the people with the highest needs are left out of the conversation. For every one of these people, our goal should be to help them reach full potential while retaining the right to choose the setting, support systems, and social environment that best fits their needs.

Finding the Right Home for Joyce

By Wayne Ryerson

On Friday, December 17, 2021, my brother Bill and I received a notice of termination of residential services from our sister, Joyce's, group home provider in the Chicago area.

Dear Mr. Ryerson,

I am writing to inform you that [x-x-x-x-x] (the group home provider) is issuing Joyce Ryerson notice of termination of residential services. Given ongoing staffing challenges at her CILA in conjunction with DSP vacancies agency wide, [x-x-x-x-x] is closing your sister's CILA. Enclosed you will find copies of your right to appeal....

When we had originally got Joyce moved from a State Operated Developmental Center (SODC) back in 2007, it had taken months - more than a year, in fact. Now we were expected to somehow find her a new home in weeks. It was a pretty helpless feeling, and I did not sleep well that weekend. There is absolutely no way that I could have taken care of my sister by myself. Her disability has rendered her super high-maintenance. The wheels would have fallen off the cart the very first day.

Our first step was to go through an administrative review process to appeal the discharge. That was handled by our sister's Independent Service Coordination (ISC) agency. An appeals packet was submitted the following week. That was the only thing that got accomplished prior to New Year's Day.

This was the holiday season. How much work do you think was actually getting done by anybody? A lot of individuals were taking time off during the holidays. In fact, entire organizations were standing down the last week of December. So we really did not have four weeks; we only had three, if that.

The result of the administrative review finally came back on January 7, 2022. They stated that they did not have jurisdiction over a facility closure. They mentioned, yet did not rule on the discharge. It was a strange ruling, to say the least.

DENIED

The next step was to request a formal hearing. Our attorney handled it. In her submission, she made it clear that we regarded this as an appeal of a DISCHARGE. (Interestingly, we had some difficulty just determining *WHERE* to send the request for formal hearing.)

Our intent was not to stop the closure of the group home; we just needed to more time to actually find a new placement. Also - and this is equally important - if we had failed to avail ourselves of the prescribed administrative process and later needed to go to court, we wouldn't have been able to. We would not have had standing. Attorneys refer to this as preserving one's legal options.

Around this time, we also obtained an extensive list of providers. I attempted to contact providers to find out if they had any openings and would they consider admitting Joyce. This didn't work out at all. For one thing, the providers did not share our sense of urgency. There were several times when the person in charge of admissions wasn't even in the office that day. Another provider just wouldn't get back with me after he had initially seemed interested. Yet another provider was extremely concerned about Joyce's behaviors.

We were expecting Joyce to be discharged the week of January 16. (If you look at a calendar, you can see that January 7 is roughly one week before January 16.) And there we were, with little progress finding a placement and no means at all to deal with what appeared to be an impending disaster.

Was this the final count-down? As the week progressed, day by day, the discharge date got closer and closer - and closer.

January 16 came and went without us receiving a call to come and get her. Our attorney arranged a conference call with the provider and their attorney. They indicated that the home would be physically closed some time in mid-February.

That still only gave us a few more weeks, but it turned out to be just enough to make a difference. While I was making phone calls and trying to identify potential providers, the Independent Service Coordination agency had been in contact with a potential provider south of Chicago. That provider had observed Joyce at home via Zoom and had agreed to admit her.

Bill and I, of course, were all in. This was our way out. We weren't going to jeopardize this deal by trying to find another provider that was closer. Problem solved, to our great relief - or so we thought. Joyce moved to her new home south of Chicago on February 11.

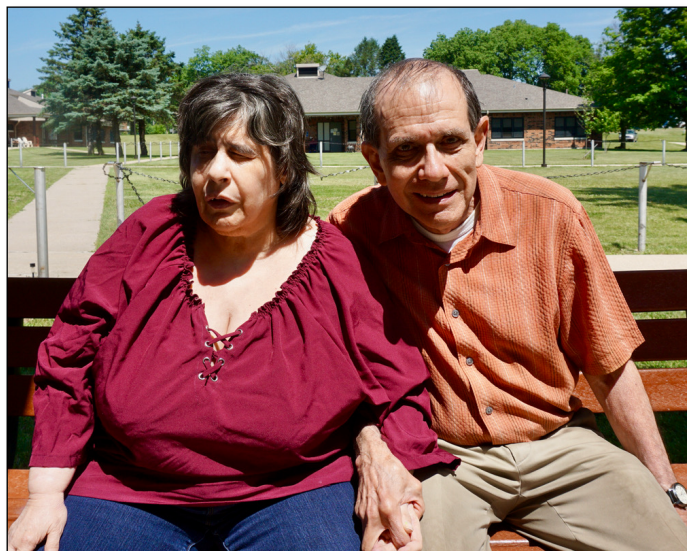
Joyce is a great sister and doesn't even know it. She is alert, charming and funny. She has a great deal of personal initiative. Not at all lethargic. Unfortunately, because of her profound disability, much of her personal energy is directed toward various maladaptive behaviors.

The new provider had not fully appreciated the impact of those maladaptive behaviors. They had put her in a group home with five other ladies - all high functioning - and only one staff. The other ladies may not have needed to be closely supervised, but Joyce certainly did. Not possible for one staff to perform her normal essential duties AND watch Joyce.

Joyce's home manager was a bright, up-and-coming young lady. It did not take her long to realize that this was not going to work out. The provider soon contacted the Division of Developmental Disabilities to get Joyce a new placement. This was a right-now problem that needed to be solved right now. It could not be allowed to continue.

From the beginning, the Division of Developmental Disabilities had assured us that if community placement could not be found, they would place Joyce in a State Operated Developmental Center (SODC). And that is exactly what happened. On March 9, she moved to the **Jack Mabley Developmental Center** in Dixon, Illinois. It's about a two hour drive each way, and I don't care. If it means that I have to get up an hour earlier to visit my sister, so what?

As we look back on this, one of the lessons is that my brother and I were NEVER in control, although we certainly tried. We were almost totally dependent on others performing their official duties.



Joyce with Wayne, at her new home at the Jack Mabley Developmental Center

The old group home provider gave us a break by keeping the home open for a few extra weeks. The Independent Service Coordination agency did a great job just to find any new placement at all. In the end, the Division of Developmental Disabilities kept their promise to move Joyce to an SODC. And our attorney was (and is) magnificent.

Joyce is doing just fine in her new home. The staff at the Jack Mabley Developmental Center are very well organized and dedicated. We are glad she is there.

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VOR's mission is to advocate for high quality care and human rights for *all* people with intellectual and developmental disabilities (I/DD) and autism.

What's Happening in Your Community?

We try to keep our members informed by posting articles from across the country in our Weekly Newsletter, and we are always looking for personal stories to include in the VOR Voice.

Feel free to submit your stories, pictures, and articles of interest to us at info@vor.net!

Dental Care for Individuals with I/DD and Autism – By Kathy Dwyer

Chair, Louisiana Dental Task Force for Adults with I/DD / Chair, Louisiana OCDD State Advisory Committee



Over the 45 years of my daughter Jen's life time, I have searched for a dentist that could work with her and her sensory/aversion issues. I was hoping she could have a dental exam and cleaning without being restrained or having to wait 5 to 6 years for an OR in a hospital each time she needed general anesthesia for a basic dental exam and cleaning. After seeing at least five different dentists and decades later, I am thrilled to say we've found one, i.e., Dr. Jacob Dent. And Dr. Dent was able to hit a home run! At least in my book he did!

This is HUGE! Because before seeing Dr. Dent, Jen would barely open her mouth for a dental exam. She couldn't tolerate a tongue depressor because of her sensory issues and sensitive gag reflexes. Nor would she sit still for an exam. Like many other parents, I am not fond of restraint. It's frightening and makes the individual less likely to want to go to a dentist appointment ever again. As time went on and Jen required more and more procedures under anesthesia, she was getting to the point where she didn't want to go to doctor appointments anymore; and would get upset if I even mentioned we had one. She was beginning to experience anxiety attacks, especially after having a bad experience with an IV for an MRI. So it became clear that I had to find another solution.

Thankfully, Dr. Dent offered to help. He first let Jen just sit in a chair in the waiting area while he took his time to talk with me and interact with Jen to get to know her and establish a relationship with her, all while keeping his distance. He then scooted closer to Jen as she became comfortable with Dr. Dent and began interacting with him. I have to admit, my expectations were fairly low, even for Jen to just open her mouth long enough for a visual exam. But Dr. Dent was able to accomplish even more! He was able to brush her teeth while doing a fairly thorough visual exam!

The techniques Dr. Dent demonstrates in the video could work with so many other children and adults with intellectual and developmental disabilities or autism. And it is exactly what I and others on the Task Force have been recommending to be taught to all dental practitioners, including hygienists. That is, taking interest in Jen (the patient) as a person and using simple, Positive Behavior Intervention and Supports (PBIS) techniques. PBIS is frequently taught to us as parents of children with intellectual/developmental disabilities (I/DD), and is how Dr. Dent learned them as a parent raising his son w/ autism. If parents can learn these simple techniques, so can dental professionals.

The Louisiana Dental Task Force has been discussing the need for PBIS since the beginning of the Task Force, 3 years ago, and has recommended it be included in a behavioral component for the enhanced curriculum required by the Commission on Dental Accreditation (CODA) for all Schools of Dentistry. We also would like to see practicing dentists trained in PBIS. Dr. Dent is preparing and submitting a Continuing Education (CE) proposal to the Louisiana Dental Association in September, and will be conducting continue education training at the Louisiana Dental Association's "Last Chance" seminar in December. The CE will include the PBIS techniques Dr. Dent demonstrated with Jen. Learning the techniques Dr. Dent demonstrates clearly will make dental exams and cleaning so much more comfortable and possible for children and adults with intellectual/developmental disabilities as well as the dentists themselves.



Success!

There are many benefits to learning PBIS. Besides being able to offer more comfortable treatment for our most vulnerable population and the general population, it will help grow a dentist's practice by being able to serve adults with I/DD AND their family members. I say family members because we would prefer our entire family be served by the same dentist. And many of us are covered by private insurance, not Medicaid, or pay out-of-pocket. What's more, it will save the state and federal government millions if not more in facility fees, general anesthesia, lab costs, etc. just by eliminating the need for dental exams with general anesthesia.

Note: The Louisiana Dental Task Force worked with LA's State Medicaid Office to establish a special billing code so that dentists may be reimbursed for the extra time needed with our loved ones. Multiple visits, up to four per year, are available for reimbursement as well, so dentists can work with our loved ones more frequently to help them become comfortable with the exam and cleaning process.

Planned Giving To VOR

Several of our members have shown interest in making charitable contributions to VOR. Here is a short overview of some of the most popular forms of planned giving. As always, we recommend that you **contact your tax professional or account administrators** to determine which type of contribution is right for you, and to ensure that your donation follows the protocols established by the IRS and the organization that administers your IRA, insurance, or other assets.

Make a Charitable Distribution from your IRA

You can make a qualified charitable distribution (QCD) from your IRA and make an immediate impact. Here's how:

- You must be 70½ or older.
- Your gift must be transferred directly from your IRA account to VOR.
- Your gift is a transfer of funds from your IRA to VOR, so while you do not receive a charitable deduction, it does not create taxable income for you.
- You may transfer up to a total of \$100,000 per year (individual) or \$200,000 (married couple).
- If you are required to take a Required Minimum Distribution (RMD) from your IRA, your gift can count towards it, but your gift is not limited to your RMD. If you are using a checkbook issued by your IRA administrator to make your gift, please send your gift as early as possible to ensure that it qualifies for a distribution in the current year.

Due to recent changes in the laws governing retirement plans, please seek advice from your financial advisor regarding the tax implications of your gift, particularly if you plan to continue to contribute to your IRA after age 70½. Your gift may not qualify for these tax benefits.

Add VOR as one of the Beneficiaries of your Retirement Plan

Naming VOR as a beneficiary of your retirement account can be an attractive option for creating your enduring legacy and reducing income and possibly estate taxes for your loved ones. Because retirement plans are taxed differently than most assets, they may become a tax liability.

Income taxes to your beneficiaries on retirement assets can be as high as 37%. This means, for example, that a \$100,000 IRA will be worth only \$63,000 when it gets to your loved ones.

Naming VOR as a beneficiary of your retirement assets generates no income taxes. VOR is tax exempt and eligible to receive the full amount, bypassing any income taxes. This means, for example, that a \$100,000 IRA given to VOR will be worth the full \$100,000.

Making Gifts of Securities

You may contribute stocks, bonds, and mutual funds that have grown in value. Potential benefits include:

- You may receive a charitable income tax deduction for the full market value of the securities (up to a maximum percentage of your adjusted gross income as dictated by tax law).
- You could avoid paying the capital gains tax on any increase in the value of the stock you give.

Making a Legacy Contribution through your Life Insurance Policy

If you have a life insurance policy that has outlasted its original purpose, you can use it (or a percentage of it) to reduce your taxes while helping people with I/DD and their families. Here's how:

- Request a beneficiary designation form from your life insurance company and make VOR a full, partial, or contingent beneficiary.
- Sign over a fully paid policy. You will be allowed a tax deduction for your generous gift.

If you are interested in any of these plans for supporting VOR, please contact Hugo Dwyer at hdwyer@vor.net or 646-387-2267.

We are deeply grateful for your gift, and for your ongoing support of our mission and our families.

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

The VOR Voice – Fall, 2022
In this issue:

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Please note: Your membership expiration date is listed at 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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CITY _____ STATE _____ ZIP _____

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MY CONTACT INFORMATION HAS CHANGED ☐

To make a memorial or honorary donation, please
visit our website at:
<http://www.vor.net/get-involved/donate-to-vor>

☐ \$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: \$ _____

☐ I would like to make an additional donation to support VOR. An additional gift is enclosed for:

☐ \$2,500 ☐ \$1,000 ☐ \$500 ☐ \$250 ☐ \$100 ☐ \$50 ☐ Other \$ _____

Make checks payable to VOR, or use your credit card: ☐ Visa ☐ MasterCard ☐ Discover

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