



# Advocacy

## in Everything We Do

Racker is more than just an organization; it's a place of belonging for people with disabilities & their families. Advocacy within the Racker community is not just a duty, but a vital thread woven into its very fabric.





**CRIS DONOVAN**  
Executive Director  
Racker

## Year-Round Advocacy

You've likely heard lots of stories about New York's budget process and the legislative process in general. Consider the lyrics from Schoolhouse Rock's "I'm Just a Bill" and the saying from Otto Von Bismarck that "Laws are like sausages. It is best not to see them being made." In New York, we've heard about "three men in a room" budgeting and the notoriously late state budget.

For better or worse, organizations like Racker rely on the New York state budget to set the rates for most of our services. These rates then determine how we can grow our service continuum, compensate our staff, and invest in new technologies. Over the years, the disability services system has not been a top priority within the state budget. We have had 0% increases in our reimbursement rates for many years despite increases in our costs to provide the services. The chart below, included in testimony to the legislature by CP State and captured by Assemblymember Kelles, demonstrates just how far behind reimbursement rates for disability services have fallen over the past 10 years. We are pleased that people with disabilities are included in recent budgets, but clearly, we have a long way to go to make up for the years of zero increases while our organizational costs (wages, health insurance, food, etc.) rose.



Sometimes learning more about a process makes things worse (the making sausage analogy) and other times we can see the heart and values underlying the process. We've been extremely fortunate to have many elected representatives at both the state and federal levels who understand the value and needs of the disability community. We've welcomed elected representatives into our programs and into discussions with our staff, the people we serve, and their families, to demonstrate the impact of the investment (or lack of investment) in the disability service sector.

Racker's advocacy work is a year-round effort; however, now is the time when we need to see our representatives lean in and speak out to ensure the support for their constituents with disabilities, the families that are impacted, and the staff who are the foundation of the service system, are not left behind.

Please join our efforts at: [www.racker.org/advocacy](http://www.racker.org/advocacy)

*Cris*





# Addressing Ableism

Diane R. Wiener, LMSW, PhD  
Racker Day Treatment Counselor



James I. Carlton's *'Nothing About Us Without Us: Disability Oppression and Empowerment'*, has led many people to believe that Carlton coined the phrase, "Nothing About Us Without Us." However, this now famous phrase began in the 1990s in the South African Disability Rights movement and was adopted later by Carlton.

"Nothing About Us Without Us" means that Disabled people must come first in any decisions and practices affecting Disabled people's lives. Whether through a self-advocacy team (created, led, and continued by self-advocates), determining who is really in charge and who gets a say at the staff leadership retreat, or ensuring there is appropriate representation on a Board of Directors for a disability-focused organization, "Nothing About Us Without Us" means that Disabled "voices" are front and center.

Disabled "voices" are many and varied. It is not okay if only certain Disabled people are welcomed. Disabled voices communicate in print, by stimming, using AAC devices, by typing, in sign language, using texting, via ProTactile's channels, with apps, verbally, etcetera. Disabled voices come from everywhere. Therefore, Disabled people's experience and expertise need to be taken into account when honoring and demonstrating "Nothing About Us Without Us."

The Americans with Disabilities Act (ADA), written into public law in 1990 and amended



Photos by Tom Olin

in 2008, is likely the most famous U.S. law concerning the rights of Disabled people. Yet, Disability Rights and, more recently, Disability Justice, have been central to activists, advocates, and allies for many years. Section 504 of the Rehabilitation Act of 1973 and the ADA (as well as its amendments) would not have been possible without disability-led activism.

Ableism means discrimination against Disabled people and relies on the incorrect assumption that Disabled folks are inferior to or somehow less desirable than able-bodied persons. While advocacy may include fighting for inclusion, activism engages with active refusal of and action taken against discrimination, whether obvious or behind-the-scenes. Ableism is always with us. Forming great committees is not always enough. Sometimes, we have to lobby our elected officials. And sometimes we have to take to the streets.

When discussing topics of diversity, inclusion and equity through the scope of belonging, we must not forget accessibility. In order to stay true to the values of the Circle of Courage, Racker's focus on activism as well as advocacy creates a path to belonging for all. 🌱



## Self-Advocacy

### 'Other Voices in the 607' Share Their Thoughts

During a recent meeting held by The Other Voices in the 607, the self-advocate members had the following to say about the budget crisis and the importance of adequate staffing: Consistency in staffing is key to our wellness. Some folks have waited over a year for staff due to the shortages. It is uncomfortable when people come and go so quickly.

Sometimes, you barely have a chance to learn about your new staff before you have to say “goodbye” and go through meeting someone new all over again. It also feels unfair when you lose a staff person because sometimes there's

someone with higher needs than you and your staff is taken away for them due to a shortage.

It also puts an unfair stress on our families when they end up taking over the role for our staff because no one else is available. We try to be independent, but it is hard to work on our bigger, long-term goals without staff to help and support. Staff are like a part of our family.

A more adequate COLA would enable these relationships to continue to grow, to help us feel safe, and to support us with navigating the opportunities we need to continue to grow. 🌳

## Embracing Family Voices Introducing Our Family Advisory Council

Racker was founded on the advocacy of families. Racker families and staff have had a rich history of partnership for over 75 years. Some of the advocacy work done by families has resulted in support of legislative initiatives, program development and program improvements.

Family collaboration happens in many ways at Racker, in both formal and informal engagement between staff, service recipients and their loved ones. In 2024, we will establish a structure known as the Family Advisory Council to create a long-term formal platform for families to be involved in advocacy efforts, program improvement and other initiatives within the organization.

This council will be comprised of diverse individuals representing the rich tapestry of families connected to our organization. Whether they are parents, siblings, or other relatives, their unique perspectives will provide invaluable insights that will help us work toward our goal of continuous improvement in services.

The goals of the Family Advisory Council are multifaceted. Firstly, it aims to establish a direct line of communication

*“The symbiotic relationship between families and agencies is the beating heart of compassionate care for our loved ones. A cornerstone of inclusive and holistic support, it nurtures a meaningful sense of community, mutual respect, and dignity. We are thrilled to see this critical initiative take off and commend Racker leadership for their unwavering commitment to partnership, transparency, and excellence.”*

*- Hongnan Ma- Mother/Advocate*

between our organization and the families involved, fostering a transparent environment. By creating this channel, we hope to gain a deeper understanding of the families' perspectives, enabling us to tailor our programs and services to better meet their needs.

Secondly, the council will contribute to informing the external advocacy efforts of the organization. The Family Advisory Council will be instrumental in ensuring that our initiatives are not only effective but also aligned with the values and priorities of the families we serve.

We believe that by actively involving families in the decision-making process, we can create a more responsive and compassionate organization that truly understands and meets the diverse needs of our community. If you are interested in hearing more about joining our new Family Advisory Council, please let us know here:







## Community Inclusion Advocacy

In recent years, the system that supports people with disabilities has faced challenges helping people be fully included in their home communities. Workforce shortages and availability of services has increased the barriers that people with disabilities are facing in accessing the richness of our local communities. Racker staff sees community inclusion as a priority and some teams are finding collaborative and creative ways to prioritize this need.

The Residential and Community Support teams have worked together to develop and implement a 100% community based program called "Meaningful Days". This program is offered part and full time and offers a blend of group and individual activities. The activities are skill building in nature and are based on the preferences, goals and desires of program participants.

Two staff in particular have become champions for advocacy in the community. Liz Ripley, Direct Support professional says "We advocate for individuals by providing them with opportunities to be involved in the community. Community inclusion is important because it promotes independence and gives individuals a sense of belonging." Liz describes her work as supporting people to determine how they want to spend their days, adding that they spend time together researching events, activities and places in the community that are of interest to participants.

Brianna Koch, Direct Support Professional describes her role as that of an advocate. While assisting people to be fully immersed in building skills and relationships she reminds them that the community is all of us. She

says "The more people that are involved in community, the stronger it is. It opens an avenue for connection and support, something that is universally beneficial. Without community inclusion, the individual might forget how important they are to it."

Brianna, Liz and hundreds of other Direct Support Professionals and Community Support Professionals are doing the important work of advocacy alongside the people they support in their home communities. Racker staff continue to find creative, collaborative and solution focused ways to continue to maintain our community focus. 🌳

CP State President and CEO Mike Alvaro testifies at the Joint Legislative Public Hearing on 2024 Executive Budget Proposal: Mental Hygiene on February 12, 2024



**Scan QR Codes for VIDEO**

Assemblymember Kelles speaks to Dr. Ann Marie T. Sullivan, M.D., Commissioner, NYS Office of Mental Health, Dr. Chinazo Cunningham, Commissioner, NYS Office of Addiction Services and Supports (OASAS) & Kerri Neifeld, Commissioner, NYS Office for People with Developmental Disabilities (OPWDD) during a joint budget hearing on mental hygiene.



# A Half Century of Advocacy - Sarah Rich Appointed Emeritus Director



Above: Sarah Rich



Scan the QR Code  
to enjoy the Swim  
Program video from  
2019.

At Racker, we have a group of friends who are known as our Emeriti Directors. These are people who have served Racker in a variety of ways, including past board service, they are long-time donors, and they have made a significant contribution to Racker overall. The Racker Board of Directors by-laws describe an Emeritus Director as an individual who has given excellent service to Racker and is held in the highest regard by the organization and the community.

Sarah Rich, Racker's newest Emeritus Director, has been connected with Racker since 1976. Sarah was a professor at Ithaca College in the 1970's and spearheaded the collaboration between Racker and Ithaca College to develop the Swim Program. The benefit and influence of the Swim Program on both preschool aged Racker students and Ithaca College students spanned well over 4 decades.

Sarah joined Racker's Board of Directors in the 1980s and has served as an Associate Director in the years since. Sarah has been a steadfast member of our Special Review Committee and was able to see several of the children she knew from the Swim Program grow into adults and move into Racker's Residential Program.

In recognition of Sarah's nearly 50-year partnership, service and advocacy to Racker, she was nominated and subsequently accepted as an Emeritus Director. This is an honorary title and is a lifetime appointment. Sarah is an avid traveler, but remains committed to volunteering when she is in town, including at the annual Racker Rivals Big Red. 🌳

## Advocacy In Everything We Do

Advocacy comes in all shapes and sizes. Each person plays a unique role in advocating for the rights, needs, and inclusion of individuals with disabilities, fostering a community where everyone feels valued and supported. It could be a parent who fosters communication and ensures their child has access to opportunities.

Advocacy is always present within the Racker community where each individual contributes their unique strengths and perspectives to create a more inclusive and supportive environment. Board members represent our community at Racker, and Racker in our community. Their advocacy is vital to employees, our programs help lead our organization.

Social media allows us the opportunity embrace advocacy in new ways. On the 8th of every month we will feature new voices and stories of advocacy- please join us for Advocate on the 8! Help us gain momentum in enacting real change: send us a message – a picture – or a video to be shared with the Racker Community. Email [info@racker.org](mailto:info@racker.org) with the subject line Advocate on the 8. Tag us or send us a message on social media with your story. Your voice makes all the difference. 🌳

## Advocate on the 8!

*"As a Board member at Racker, I believe that one imperative on any advocacy efforts at the board level is to learn about and understand the issues that staff and the people we serve face on a daily basis from their perspective. We need to have conversations about what needs to change and and collaborate with staff and individuals receiving services on solutions that work for everyone. If we want the staff and folks we serve to know they belong, it's their voices that matter, and it is incumbent on the Board to support our people and try to continue to ensure that staff and clients have access to the tools and resources needed to make that possible."*

- Emily Papperman

Current Racker Board Member, past Board President

# Family Partnerships

## Fostering Advocacy in Early Childhood Programs

Part of Racker's mission in early childhood education is to create and foster a meaningful partnership with families during their child's journey in education. Families and Racker's early childhood team come together as partners to create a holistic and individualized plan for each child. Advocacy is a major component in building a partnership that matters.

In situations when a parent feels too anxious to talk to their child's teacher; when a student needs encouragement to ask for help in the classroom; or even when a grandparent feels as though their perspective is not being validated - this is when to call on advocacy.

Advocacy can be broken down into small yet meaningful steps that foster a strong partnership between families and early childhood educators.

### Advocacy in Education is:

#### ***Listening:***

Listen reflectively with the intent to gain a better understanding. Listening goes hand in hand with validation.

#### ***Validating:***

Show parents that they are heard, and they are supported. Validation is encouraging.

#### ***Encouraging:***

Encourage parents to share, to reach out, and to be part of the team. Encouragement is empowering.

#### ***Empowering:***

Early childhood education professionals help parents and caregivers understand that they hold special knowledge of their children, and that knowledge is their power. Empowerment is advocacy.



*Joelle Silverman-Hrubes with student*

Advocacy in education is working alongside families and showing them that their voice holds value in all spaces.

Advocacy might sound like, "I hear what you're saying. Can you say more about that?" or "That must be hard. How can we help?" Sometimes it means asking tough questions, "Did you hear what dad said about that plan for kindergarten? I think he may be anxious about it. How can we include his perspective?" Asking questions is a two-way street between families and Racker professionals. Let's ask more questions! Asking questions IS advocacy.

Advocacy in early childhood education is not about being someone's voice, it's about taking small steps to strengthen a voice that is already there. If a parent or caregiver feelings listened to, validated, encouraged and empowered enough to use their voice in the earliest years of their child's education, it will continue to grow stronger in each relationship and at each table they sit at throughout their child's journey in education. 🌳



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## OUR MISSION:

We support people with disabilities and their families to lead fulfilling lives by providing opportunities to learn and be connected with others.

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