PENNSYLVANIA DEVELOPMENTAL DISABILITIES COUNCIL



2021
IMPACT
REPORT

* SPRING NEWSLETTER

NOTE FROM THE EXECUTIVE DIRECTOR

I hope you enjoy our combination annual impact report and spring newsletter. Council has been active and busy during the past year, including much work to update our mission and vision. Our discussions led us to move away from "building inclusive communities" to "support communities so that all people belong" and strengthened language to "empower people with all disabilities" rather than merely working on a cross-disability agenda. The Council also added "pursue equity for all people" to explicitly state our commitment to address the needs of individuals who are underserved, underrepresented, and experience disparate impacts due to systemic failures.

Our annual impact report, which is typically presented in early spring, was delayed due changes in our federal reporting timelines. We hope you feel that it was worth the wait as much as we do! The report highlights just some of the important work completed during 2021. As we wrapped up our last State Plan, we express gratitude and pride in the work done by all of our grantees. We made significant progress in meeting our social and system change goals and will build on those successes in our next plan. Look for our next *Request for Applications* publication this fall to see what work we have planned in the coming years.

In closing, I want to thank the Council members, our grantees, advocacy groups, and the system personnel who worked diligently to respond to and address the challenging issues faced during the pandemic. As our community rebuilds and recovers, the Council will continue to collaborate with our DD Act partners, support our grantee network, offer community response funding, and work with advocacy organizations to address needs and improve the lives of people with disabilities and their families.

Lisa A. Tesler, Executive Director

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PADDC MISSION

The Council engages in advocacy, systems change, and capacity building with people with developmental disabilities and their families in order to:

- Support people with disabilities in taking control of their own lives
- Ensure access to goods, services, and supports
- Support communities so that all people belong
- Empower people with all disabilities
- Promote the understanding of the life experiences of people with disabilities
- Pursue equity for all people

PADDC GOAL AREAS

from the 5-year State Plan that ended in 2021

GENERIC SOCIAL CHANGE

The outcome of the generic change goal was to increase the capacity of and to challenge generic communities and systems to ensure that the systems and supports that are available to the community in general are made equally available, with appropriate accommodation, to Pennsylvanians with disabilities.

SYSTEMS CHANGE

The outcome of the systems change goal was to work toward making positive changes in systems that impact people with disabilities in Pennsylvania to ensure that they have access to the goods, services, and supports they need to be engaged and active members of their communities.

EMPOWERMENT

The outcome of the empowerment goal was for an increased number of people with disabilities and their family members to become actively engaged in activities that give them increased choice and control in systems that directly impact their lives and in the communities in which they live.

COLLABORATION

This year, due to the pandemic, most collaboration efforts focused on mitigation of risk, addressing immediate health and safety needs, recommendations for practices to increase accessible resources and information for the IDD community, and to assure equal access to vital PPE, healthcare, and treatments.

CROSS-DISABILITIES

The outcome of the cross-disbilities goal was to create increased opportunities for communication around the impact of shared stigma and segregation.

STIGMA

The outcome of the stigma initiative was to increase the public recognition that disability is a natural part of the human experience and just one aspect of the human condition.

TARGETED DISPARITY

The outcome of the targeted disparity goal was to lessen or eradicate the level of disparity experienced by marginalized groups.

PADDC VISION

We envision a commonwealth where all people are valued and thrive.



QR Code Introduction

Throughout this publication, QR codes are used to provide links to additional information. Instructions for how to scan the codes is included below. The code on the left will open the PADDC website once scanned.





Scan QR code to visit paddc.org.

How to Scan a QR Code with an iPhone or iPad

- 1. With a QR code nearby, open the camera on your iPhone or iPad.
- 2. Position the camera so the QR code is in frame. Your iPhone or iPad should scan it automatically, without any input needed from you.

Once it scans the code, a notification will appear at the top of your screen with the link to the QR code's content. Tap this and you'll be brought to it.

How to Scan a QR Code with an Android Phone or Tablet

- 1. With a QR code nearby, open the camera on your Android device.
- 2. Position the camera so the QR code is in frame. Your Android should scan it automatically, but if it doesn't, press and hold your finger on it.

You'll be given the link that the QR code leads to, and a choice to open it, copy the URL, or share it.

If this doesn't work, download the Google Lens app from the Play Store. This app's QR scanner is one of its major features.

Rural Healthcare Access

PADDC's efforts to target disparity in rural healthcare access has engaged people with developmental disabilities and their family members in advocacy, capacity building, and systems change to ensure generic healthcare locations, equipment, and services in rural Pennsylvania are accessible to all.



Pennsylvania Health Access Network (PHAN) used a PADDC grant to develop Healthcare Access for People with Disabilities in Rural Pennsylvania. The report is based on over 300 conversations with community members with disabilities, their family members and caregivers, and community based organizations. Through these conversations, PHAN learned that while many healthcare professionals are effectively treating patients with disabilities, many others have a lot to learn.



Many of the individuals who contributed their stories to this report are now working with PHAN to improve access to healthcare locations, services, and equipment in rural PA.

Scan QR code to read full report.

Following up on the stakeholder listening sessions they conducted, PHAN continued their advocacy work with state agencies to ensure the voice of people with disabilities is heard. As a result, the Office of Medical Assistance Transportation Programs (MATP) has begun to take next steps in the rollout and implementation of various suggested improvements including an agreement to cover transportation to COVID-19 vaccine appointments regardless of Medicaid provider status—and some counties even provided free trips for non-Medicaid recipients.

Because of the education and support we received, we were able to share our experiences at healthcare appointments directly with our providers. We can't stress enough the importance of communication between parents and providers, as well as the importance of providers educating themselves on the unique needs of patients on the autism spectrum and those with other disabilities.

- Tammie S., Mary B., and Cara S.

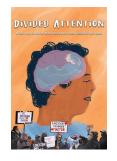
School to Prison Pipeline - Diversion

The Education Advocacy Program at Delaware County Advocacy and

Resource Organization (DCARO) received a grant for a project aimed at combating the School-to-Prison Pipeline. The program was implemented in the Chester-Upland School district, and provided teacher and student training in research proven techniques (Mindfulness and Collaborative and Proactive Solutions) to develop emotional and behavioral regulation skills with the goal of reducing punitive practices.

The success seen at Toby Farms School, a public middle school, has influenced Chester Upland School District to expand the program into other schools within the district.





In partnership with PhillyCam, DCARO embarked on a documentary film project called "Divided Attention," which is meant to serve as a call-to-action to address inequitable school funding for varied audiences such as students, parents and community members. The film also serves to model how mindfulness skills instruction could be implemented in schools to impact students' social emotional wellbeing and potentially replace punitive practices.



Scan QR code for more details on the documentary, "Divided Attention." Tamia, an African American student with mental health and anger issues, learned to control her emotions, including panic attacks, better through the mindfulness training she received at Toby Farms School. In the documentary film, Tamia shares with the audience her struggles with anxiety and anger. Tamia said that there were times when she did not feel safe in her own home, and she talked about the threat of being put into a mental hospital.

She also shares the difficulties she faced when she began to question her sexuality and learned that she was gay, including her tendency to isolate herself from others.

Self-advocacy Support

PADDC's self-advocacy led organization is **Self Advocates United as 1** (SAU1). SAU1 envisions a world where people with developmental disabilities and their families are united to share knowledge, empower others, and use their voices to transform their communities and people's lives. The SAU1 board of directors and other voting members include people with disabilities from all over the state of Pennsylvania.





Due to COVID-19, all of SAU1's work had to be accomplished through virtual methods. Their Zoom events, particularly their "opening" slides where they fully explain with both graphics and words, how to use Zoom were recognized for their excellence—and now, many groups and organizations in Pennsylvania adopted this practice, including PADDC.

Their weekly meetings include a series of education and training events, which they offer regularly, and include:

- You're Not Alone (Let's Talk about Mental Health)
- Let's Relax Yoga and Meditation
- Let's Talk about Relationships
- Let's Talk about the Covid-19 Vaccine

Scan QR code to access SAU1's calendar of events.

SAU1 initiated an advocacy effort that included only sharing announcements and materials that were accessible. To facilitate this, their communications coordinator developed standard basic guidelines about how to make materials accessible so other organizations could build their capacity and several groups have embraced this opportunity. Additionally, they have created system change by advocating for captioning, without the need for someone to specifically request it. Their advocacy was heard and the Office of Development Programs (ODP) in PA is now providing captioning automatically for virtual meetings and events.

A young trans man who attended one of the "You're Not Alone" presentations shared that he has never felt so accepted, and knowing that other people care and are there has made a difference in his life. Person Directed Housing and Services Demonstration

PADDC focused all housing advocacy, capacity building, and systems change efforts towards ensuring people with disabilities have the knowledge to obtain housing of their own choice, are able to advocate for what they want, and are supported to create system change that enables their wants to be implemented within the systems they navigate.

Throughout the duration of their project, **Pennsylvania Health Law Project** created opportunities for input with housing providers and for advocacy. At a structured housing demonstration meeting, participants learned about gaining access to the housing system, but more importantly, the developer learned from participants about what kinds of residential environments may be successful for adults with autism.

As a part of their project, **Values Into Action** piloted a training on assessment tools and documents to assist people with developmental disabilities to obtain and maintain housing independent of services. Based on the feedback from participants, a toolkit containing all of the resources will be produced.

O. and N. live on their own in a rental apartment in Ardmore, PA. Their housemate relationship is now 1½ years old. With the support of their service provider, they have established schedules and routines for meal-planning, shopping, and other household chores. They have learned to navigate sharing and negotiating their individual preferences. They have learned how to spend leisure time. Both have jobs in the community (now resumed after COVID furloughs).

Their success, and their willingness to share their story with their peers, is yet another example of how the project has improved the lives of people with developmental disabilities.

Stigma

Council's overall goal with the Stigma initiative was to increase the public recognition that disability is a natural part of the human experience and just one aspect of the human condition.

Disabled In Action used their grant to develop curriculum resources and events to engage students in conversations around acceptance and inclusion to educate and inform them about disability in a positive and/or neutral way. The goal of bringing disability into education was to prepare the next generation to grow up without the prejudice that ignorance can create—reducing stigma and bullying, and thereby creating educational environments for all.





Scan QR code to access free lesson plans and resources.

The new school Champion program paired teachers with mentors who are disabled educators with years of experience in developing inclusive practice in schools and colleges. Students in these classrooms reported an understanding of disability and a desire to welcome and include all peers regardless of their disability. The college and university portion of this work has taken on a life of its own and is now fully sustainable at each institution.

Additional supporting activities have included disability film festivals (over 400 participants), Disability Arts 101 Workshop, and networking to build a statewide coalition for disability education.

Before working with the Champion program, I struggled with incorporating disability acceptance into our daily lessons and routines. Now, I am able to better my knowledge and understanding about disability equality and spread my understanding to every teacher and student within my school.

- Rachael, elementary school teacher

The Champion program is an amazing resource for educators looking for guidance on how to bring ideas, materials, and experiences into the classroom to educate their students on disability - past, present, and future. This mentorship program has helped me grow as an ally and become a better teacher to all students.

- Anna, high school teacher

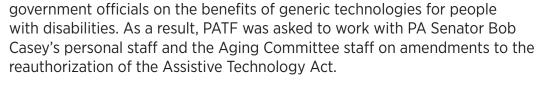
Generic Technology

The Council continued to make progress toward achieving its generic technology objective through the **Pennsylvania Assistive Technology Foundation** (PATF), our generic technology grantee.

PATF educated the public on smart home and assistive technologies through a variety of platforms including blogs, newsletters, social media, and events. At least 890 Pennsylvanians participated in events hosted by various disability advocacy and support organizations, as well as commercial organizations.







The project's outreach included informing lawmakers and other

Smart Homes Made Simple: Your Guide to Smart Home Technology was written to help people with disabilities and older adults learn to successfully integrate smart home technology into their homes and lives. In addition, PATF's advocacy work during the project enabled people with disabilities to get the assistive technology they needed. Their efforts were extremely successful and were featured in several national publications.



Scan QR code to access Smart Homes Made Simple: Your Guide to Smart Home Technology.

Before the smart home technology was installed, my aides had to stay close by in case I had a seizure. These devices have helped me to maintain my independence and reduce stress.

- Josh

My smart home technology gives me greater independence and confidence to live on my own. I just want to live in a house like everyone else without having other people around if I don't need to. This technology makes that possible.

- Alexa

Meetings Coordination

PADDC expanded the scope of work performed by our Meetings Coordination grantee last year.

In addition to facilitating virtual Council meetings, the project enabled individuals with disabilities to attend trainings, events, and education sessions through

Leadership, Empowerment and Advocacy Fund (LEAF) Scholarships. Those who attended events reported:

- They were better informed about disability rights
- They increased knowledge about accessing the disability service system
- He was more able to speak up for himself and for others with disabilities
- They were more willing to try and learn new things
- She was happy to know that she could do what she wanted to do
- They were now prepared to help others find the services they want and need
- He was ready to advocate to make his life better

A second new initiative that was implemented under this grant awarded funds for **Community Response Projects**, which provided supports to people with developmental disabilities who have been affected by a local, statewide, or national natural disasters, including concerns related to the Covid-19 pandemic. Through these efforts, a total of 368 people were reached, including 220 individuals with developmental disabilities and their family members.



Leadership

Empowerment



Scan QR code to learn more about yearround funding opportunities.

> After attending the LifeCourse Ambassador series through a LEAF Scholarship, I have been empowered to not only be a better advocate, but also use the tools to problem solve and plan for the future. It has also helped me empower my daughter to be a self-advocate.

> > - A.W.

2021 VIMPACTS

individuals with developmental disabilities and family members were helped through the COVID-19 call center



PADDC ADDED

3 new citizen Council members

- Pam Khare
- Ann Marie Licata
- CJ Rine

2 new organizational Council members

- -Charlie Miller, Art-Reach (private non-profit)
- Karen Plummer, Voice and Vision (local and non-governmental agency)





Scan the QR code to access the Transition Discoveries website.

Through PADDC's
Transition grant, a
framework for communitydriven action planning
has been developed and
refined into a website
and app called **Transition Discoveries**.

This one-stop shop empowers young people with disabilities, families, and stakeholders to engage in effective transition practices that are driven first, foremost, and always by the strengths, dreams, and goals of young people with disabilities and their families.

This project model is currently in use at **30 sites in Pennsylvania** – with more locations on the way.

Integrate for Good

is PADDC's Civic
Engagement grantee.
They empower students
and adults of all abilities
to share their talent
through inclusive
volunteerism, community
leadership, and
meaningful employment.

Since the early days of the pandemic, Intregrate for Good has produced *Hanging with Heather*, a weekly Facebook Live show.

The brilliant and talented host is Heather Michaelson. Heather redefines how many people think about Down syndrome. She's an educator, an artist, a chef, a baker, and



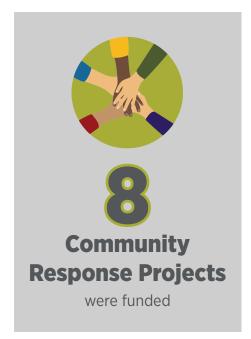
a Facebook Live host! In these 20-minute interviews, Heather interviews politicians, nonprofit executives, entrepreneurs, professors, business owners, and people of all abilities about their education, employment, business, disability, volunteer activities—or whatever they would like to share!

This regular series is a way

of shining a light on the people, businesses, and organizations in our shared community while empowering a talented, neurodiverse leader in meaningful, inclusive employment.

Scan the QR code to visit the Integrate for Good Facebook page.









DD Act Network

Activity and Impact

PADDC, under the direction of executive director, Lisa Tesler, participated in an expanding number of collaborative networking and advocacy activities. The impact of these activities can be seen in systems and social change throughout the commonwealth.

Highlights from 50+ Systems Change Activities Conducted in Fiscal Year 2021

- Drafted and sent a set of recommendations to legislators who were responsible for allocating American Rescue Plan funding
- Sent a letter to Governor Wolf and the members of the Vaccine Task Force requesting a specific vaccine allocation for individuals with intellectual disabilities and targeted support from the Office of Developmental Programs (ODP) to assure individuals would have support to access the COVID-19 vaccine
- Secured an agreement between the DD Act Network, the Department of Aging, and the Office of Developmental Programs to support a call center for individuals with intellectual and developmental disabilities, their families, and staff to access the COVID-19 vaccine
- Participated in the Coalition for Inclusive Community that met monthly and closely monitored the legislation proposed to halt the closure of White Haven and Polk State Centers
- Participated in the quarterly meetings of the Governor's Employment First Cabinet
- Participated in the Information Sharing and Advisory Committee (ISAC) workgroup to address racial disparity in the ODP system
- Chris Grandy, Council co-chair, represented Council on advocacy calls with Senator Casey's office

Sample of the Outcomes Achieved from Advocacy Efforts

- American Rescue Plan funding included services for individuals on waiting lists, increases in caps on funding limits for the Person/Family Directed Support (PFDS) Waiver, training investments for individuals and families, rate increases for providers, support to transition away from congregate day services, investments for more individualized housing and supported living, funding to move people out of institutions, and resources to address direct workforce shortages.
- People with disabilities, their families, and staff living in community settings, were moved to a higher priority for vaccine allocation.
- Vaccine rates, COVID data, and trends by setting and county, were used to improve communication and outreach efforts. Direct assistance to individuals, families, and staff for vaccinations was made available.
- Appendix K emergency provisions for the waiver programs included flexibilities to assure services were available during the pandemic.
- State Center closure efforts moved forward and individuals moved from institutions into the community.
- PADDC presented best practices and participated in a statewide conference as part of the Technology Taskforce.
- Council projects were featured at the Everyday Lives Conference.



Council Leaders Elected

New chair and vice chair begin two-year term



At the January 2022 Council meeting, Koert Wehberg and **Rob Oliver** began serving as chair and vice chair of the Pennsylvania Developmental Disabilities Council.

Koert is a senior attorney with the U.S. Department

of Education's Office for Civil Rights Philadelphia Office, where he resolves discrimination complaints filed against school districts, universities, and other education entities.

From 2019-2020, Koert was the Executive Director of the Mayor's Commission on People with Disabilities in Philadelphia, where he developed policies to support and advocate for Philadelphia's residents with disabilities.

Koert has over a decade of litigation and legal advocacy experience. He started his career by representing lowincome people of color with disabilities at New York Lawyers for the Public Interest, Inc., in New York City. In 2011, Koert moved to Philadelphia, where he began working at Disability Rights PA.

At Disability Rights PA, Koert achieved a landmark victory in 2016 when he and one of his colleagues settled a class action lawsuit against the state, requiring

Q&A (Question & Answer) With Koert

Q: What is it about PADDC that motivates you to lead the organization?

A: As a person of color with multiple disabilities, I have always been passionate about advocating on behalf of marginalized communities. My almost fifteen year career as a disability rights attorney and advocate has cemented my commitment to ensuring that all people with disabilities have access to a community that they can belong to.

I sought to be the chair of the Council because I wanted to continue its exemplary work expanding opportunities for people with developmental disabilities in the Commonwealth. I felt that my lived experience and leadership qualities could continue to advance the Council's mission and vision as we seek to move beyond the Covid-19 pandemic and adapt to our new changed landscape.

Q: What priorities do you hope to advance during your term as chair?

A: I have several priorities that I would like to focus on as Chair. First, as we have many new Council and Committee members who have spent all of their time until very recently

(continued on next page)

Council Leaders Elected (Continued)

Pennsylvania to provide applied behavior analysis therapy for approximately 40,000 children with autism.

He is the former chair of the Legislative Committee of the Pennsylvania Rehabilitation Council and a recipient of the 2020 Syracuse University College of Law Alumni Honors Award.



At 21 years old, **Rob Oliver** sustained a spinal cord injury while body surfing in North Carolina. The injury left him paralyzed from the chest down with limited use of his arms and hands. These limitations forced Rob to take a long hard look at life, relationships, and success.

After much encouragement, Rob decided to share these lessons with others as a speaker and author. His book credits include two autobiographical books. Still Walking and Still Falling. He also wrote Who Me, Yeah You! an anti-bullying book for elementary aged children.

As a speaker, Rob has shared his message with thousands – speaking at companies, schools, associations, and conferences as well as multiple radio and TV appearances. He has twice been recognized with the annual "Best of..." award as the #1 rated motivational speaker in his hometown of Pittsburgh.

Q&A With Koert (Continued)

interacting with each other through tiny boxes on Zoom and I would like to prioritize getting them fully involved in Council activities and interacting with and learning from veteran Council members. Relatedly, as new vacancies become available, I would like to increase the diversity of the Council in order to better reflect the demographics of the Commonwealth.

In addition, I am planning to work with the Council to improve our materials to ensure that they are presented in plain language and can be understood by all Council and committee members as well as members of the public who may not be familiar with the acronyms and technical language used by many of us. This goal also extends to the grantees who receive our funding. We should be able to receive plain language materials on projects that we fund so we can better determine the impact of our advocacy.

Finally, I would like to work with Council to consider whether our current meeting structure is the best way for us to communicate and move our mission forward. As I seek to implement these goals, I look forward to doing a lot of listening to integrate the views of the Council, its staff, grantees, and members of the public.

Q&A (Question & Answer) With Rob

Q: What is it about PADDC that motivates you to lead the organization?

A: I firmly believe in the Council's commitment to empowering individuals with disabilities and creating generic social change to ensure that our Commonwealth is a place that sees the value of all individuals. The importance of individuals with disabilities having access to goods and services as well as having the information and power to make their own choices about their lives cannot be overstated. I feel strongly aligned with the Council'a purpose and am honored to be part of the leadership.

Q: What priorities do you hope to advance during your term as vice chair?

A: During my tenure, I want to hear from people with disabilities across the Commonwealth about what they are facing and the issues they identify as most essential. A foundational step is to increase awareness about the Council within the disability community to help us build relationships and open avenues of communication – to ensure that we are working on the issues that are most important to the people we serve.

New Resource Available

PADDC Accessibility Toolbar





Scan QR code to access the full ReciteMe Toolbar User

Guide.

To help website users access our content in a way that works best for them, PADDC has installed the ReciteMe Toolbar.

You can now activate this set of customizable tools by clicking "Accessibility & Language" located at the top, left corner of any page on our website.

Choose from a range of features including translation into over 100 languages, text to speech functionality, reading aids, and styling options. This includes adjustments to color, font type, and size.

Tool Descriptions

Screen Reader









- All content read aloud in a natural voice
- 35 different language options
- Speed controls and Word by Word highlighting for total customization
- MP3 download to listen to content offline

Styling











- Text size and color
- Website background color
- Text font type, including Open-Dyslexic
- Text only mode to eliminating all styling, much like a Word document

Reading













- Ruler to read line by line
- Reading Mask to eliminate distraction
- Magnifier to zoom in to sections of text
- Fully integrated dictionary and thesaurus
- Margins to reposition text in text-only

Translation



Recite Me quickly and easily translates on demand all your web content into over 100 languages, including 35 text to speech voices

ADVOCACY

Tip of the Month

Be passionate about what you are advocating for to have the most impact.



We asked **Oscar Drummond** of Self Advocates United as One (SAU1) to tell us about being a disability advocate.

Oscar has had many roles in his lifetime. In his 15 years with SAU1 he has served as:

- A founder of the organization
- Board president
- President emeritus
- Ambassador

He describes his current role, lead ambassador, as being a mentor and teacher for his fellow ambassadors on how to be great advocates.

Oscar believes the key is to be passionate about what you are advocating for to have the most impact. Over the years, Oscar has built a reputation for being a strong and capable advocate. Knowing people find him credible empowers Oscar and gives him the push to know that when you speak out, you can make a difference. He also told us to remember that words have power.

"Sometimes people want to tell their story first. And that's important. But you have to remember it isn't always about you. It is about what you are advocating for. Especially when you are advocating for others, you need to make it about everybody."



Tell us who you are and what you do.



You may be asked to speak in our Self Advocate Spotlight Series.

Please email ra-pwpaddc@pa.gov or call 877-685-4452.



SELF ADVOCATE SPOTLIGHT SERIES!

- First at something?
- Create a new organization?
- Run a business?
- File and win a lawsuit?
- Help create legislation?
- Advise policymakers?
- Write a book?
- Show your art?
- Train or teach people?
- Discover something new?
- Only person to do what you do?

2022

Council Members

Koert Wehberg, Chair • Rob Oliver, Vice Chair

Nicole Adams, Representing the Secretary of the Department of Health
Dana Barone, Representing the Secretary of the Department of Labor
Lisa Butler

Heidi Champa, Representing the Secretary of the Department of Aging

Mary Kay Cunningham, Representing the Institute on Disabilities at Temple University

Keith Focht, Representing the Secretary of the Department of Education

Beatriz Frometa

Jennifer Garman, Representing Disability Rights PA

John C. Grandy

Poornima Khare

Ann Marie Licata

Maria Martin

Charlie Miller

Melissa Murphy

Amy Mathewson Nieves

Karen Plummer

Nancy Richey

CJ Rine

Jean Marie Searle

Lea Sheffield, Representing the Secretary of the Department of Human Services

Lisa Sportelli

Committee Members

Renee Benise Celia Feinstein
Robert Cummings Amy Mchugh
Juan Dipini Debbie Rozear
Rachel Frometa Melissa Ann Suarez

Melissa Hawkins





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