Legislative Panel
March 17, 2022

1:00 – 1:10 **Introduction**

1:10 – 2:10 **<u>Direct Support Professional (DSP) Workforce Crisis</u>**

Mark Davis
President and CEO, Pennsylvania Resources for Autism & Intellectual Disabilities (PAR)

Video: *Telling Our Story - Individuals and Families*

LaToscha Charles
Direct Support Professional and Resident Advisor, Emmaus Community

Nancy Murray
President, The Arc of Greater Pittsburgh, and Senior Vice President, Achieva

Elizabeth (Liz) Humphrey
Self-advocate

Sandi Shaffer Sipes and Kate Hall
Mother and daughter impacted by crisis

Kim Love
Chief Operating Officer, InVision Human Services

Patrick DeMico
Executive Director, The Provider Alliance

2:10 – 2:55 **<u>Access to Mental Health Care</u>**

Laurie Barnett Levine
Chief Executive Officer, Mental Health America of Southwestern PA

Susan Evans RN, MSN
Director of Psychiatry and Mental Health Services, St. Clair Hospital

John Eliyas
Executive Director of Adult Behavioral Health in Western PA, Merakey

Susan Coyle RN, MPH
Chief Executive Officer, Chartiers Center

2:55 – 3:00 **Closing**

Direct Support Professional Crisis

BACKGROUND, IMPACT, AND LOOKING AHEAD

MARCH 2022

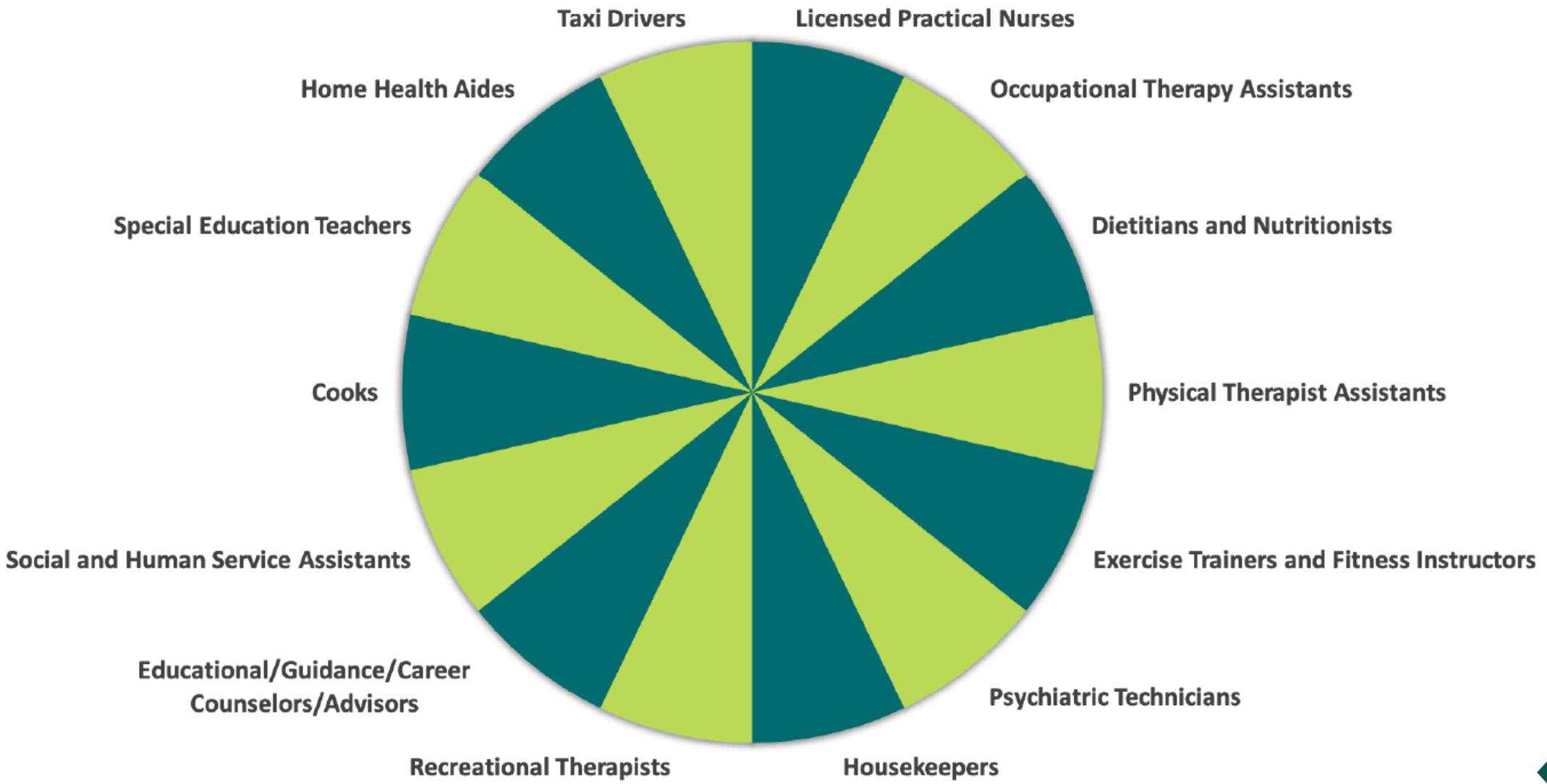
Pennsylvania Advocates and Resources
for Autism and Intellectual Disabilities

The Many Roles of a DSP

Direct Support Professionals (DSPs) support individuals with intellectual disability or autism (ID/A). At their core, the DSP's job is **to provide life sustaining support** to individuals with ID/A and help them live independent and meaningful lives in their homes and communities.

"We do what we do because we enjoy seeing the individuals we support living their best lives and reaching their highest potential. We just love what we do!"

– Betsy Harr, DSP at The Arc of Cumberland & Perry Counties


Taxi Drivers
Licensed Practical Nurses
Home Health Aides
Occupational Therapy Assistants
Special Education Teachers
Dietitians and Nutritionists
Cooks
Physical Therapist Assistants
Social and Human Service Assistants
Exercise Trainers and Fitness Instructors
Educational/Guidance/Career Counselors/Advisors
Psychiatric Technicians
Recreational Therapists
Housekeepers

In order to safely and effectively carry out these many roles, DSPs complete an abundance of annual training requirements

Direct Support Professional Wages

- Despite their many roles, responsibilities, and training requirements, DSPs have been chronically underpaid and undervalued
- The pre-pandemic average wage of a DSP was **$13.20/hour**
- In order to be sustainable, DSPs would need to be paid **$31.48/hour** according to the MIT Living Wage Calculator.
- DSPs need an additional **$18.28/hour** to reach a living wage

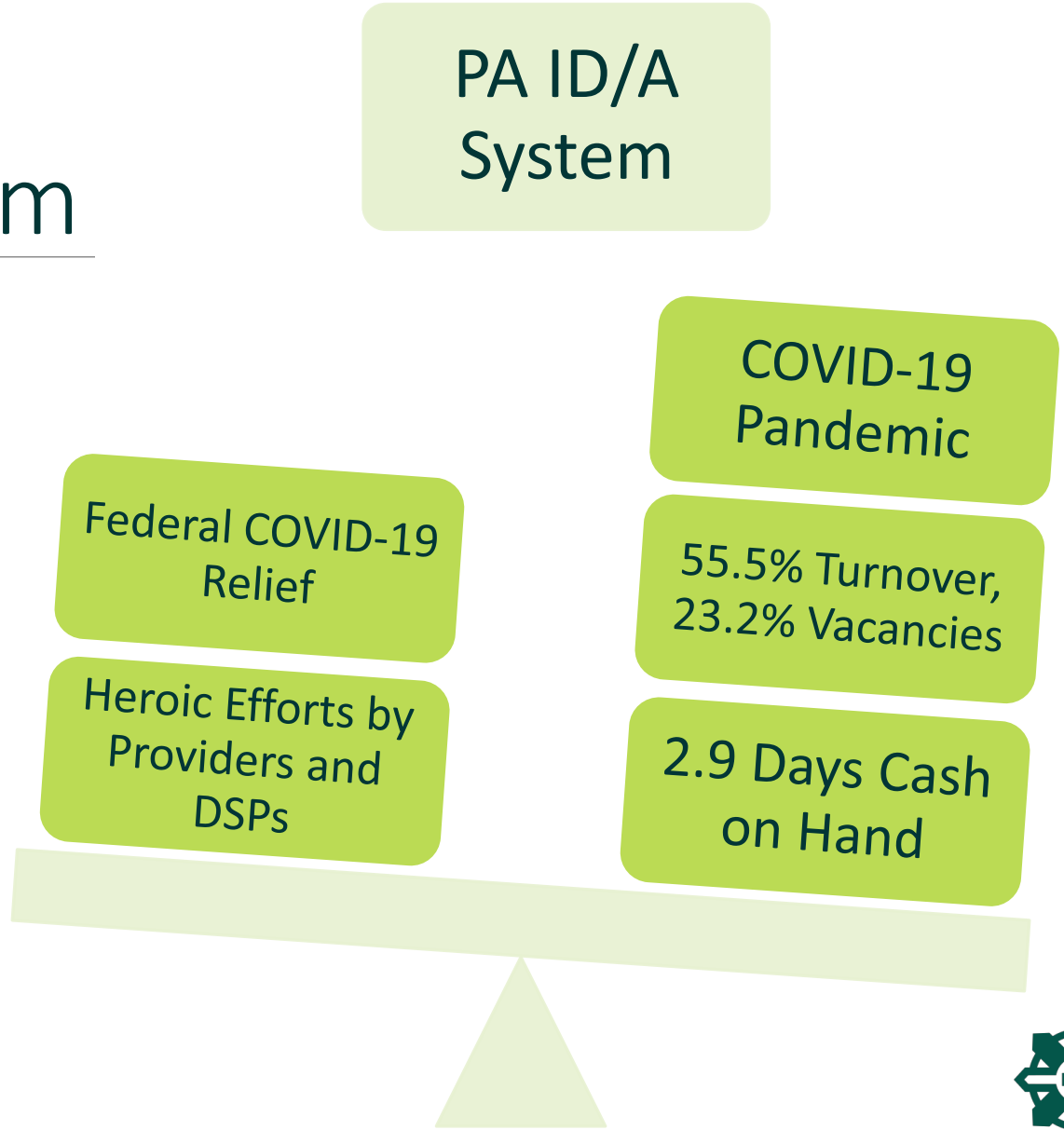
Sources:
CDI (2022). Pennsylvania ODP-Administered HCBS Proposed Rate Revisions Impact Analysis.

An Unsustainable System

The chronic underfunding of the ID/A system has led to the current crisis. The COVID-19 pandemic has only exasperated this crisis.

Providers have been unable to recruit and maintain the staff needed to support all individuals with ID/A. Currently, there are 12,224 individuals on the waiting list.

Sources:
CDI (2022). Pennsylvania ODP-Administered HCBS Proposed Rate Revisions Impact Analysis.
CDI (2021). COVID-19 Pandemic Impact on the Pennsylvania ID/A Workforce Crisis.



An Unsustainable System – Reduced Capacity

Service Type	Change in Number of Individuals Served from 2019 to 2021	% Change
Transportation Trip	-435	-67%
Vocational Services (2390)	-1203	-61%
Adult Training Facilities (2380)	-2257	-49%
Employment Support	-136	-19%
In Home and Community Support	-515	-12%
Lifesharing (Residential)	-28	-4%
Community Homes (Group Homes)	-177	-3%
100% Community Participation Support	-20	-3%

Source: PAR (2021). Impact of the COVID-19 Pandemic on Intellectual Disability/ Autism Service Capacity Survey.

An Unsustainable System – Recruitment and Retention

- 55.5% DSP Turnover, up from 31% pre-pandemic
- 23.2% DSP Vacancies, up from 18% pre-pandemic
- Only 9.4% of applicants for DSP position work more than 30 days
- Providers are using management and upper-level management to fill DSP shifts
- 15.6% of compensation paid to DSPs is at an overtime rate

Source: CDI (2021). COVID-19 Pandemic Impact on the Pennsylvania ID/A Workforce Crisis.

Barriers to DSP Recruitment and Retention

Responses from DSPs to the DSP Barriers Survey	
64.50%	Heightened COVID19 risks to self or members of household
42.10%	Wages
39.50%	Home Schooling/Educating Children at Home
36.80%	Poor Health/Higher risk
35.50%	Child Care
27.60%	Family Care
17.10%	Family Instability
15.80%	Food Insecurity
14.50%	Health care and insurance
6.60%	Transportation
3.90%	Housing

Source: Alliance CSP, MAX, PAR, RCPA, The Arc of Pennsylvania, The Provider Alliance (TPA), and UCP of PA (2020). COVID-19 Impact on Direct Support Professionals and Providers of Intellectual Disability/Autism Services.

Looking Ahead

- DSPs are the backbone of the system, do complex work, and are severely underpaid
- Long-term underinvestment in DSPs has created a workforce crisis that threatens the ID/A service system
- The future of the system is dependent upon a two-pronged approach:
    1. The need to invest in the system to provide our DSPs a living wage of $31.48/hour to support the complex and difficult work they do every day. While the rates as proposed are a good step, we must continually make steps each year to achieve this goal
    2. Implement reforms to the system that eliminate policies that don't add value to the lives of the individuals served, reduce burdensome processes on providers, and generate cost savings through efficiencies and improvements.
- Only a comprehensive approach to fixing this system will ensure its sustainability moving forward.

FY 22/23 Budget Request

IMPLEMENTING A MARKET-BASED INDEX FOR THE RATES

- Our system is fully dependent on state and federal funds, we cannot raise prices to meet competitive wages or cut services to save money
- Connecting rates to an inflationary adjuster will allow for predictable and reasonable budgeting, and continued investment in DSPs

LEVEL UP FOR ID/A - A SYSTEMS REFORM BILL THAT:

- Requires no appropriation from the Commonwealth
- Shifts towards an outcome and person-centered approach to services
- Reinvests any savings into the waiting list or DSP wages

END PRUDENT PAY

THE CONTINUATION OF REGULATORY FLEXIBILITIES

REDUCTION OF PA'S WAITING LIST

- The pandemic and workforce shortage has halted progress in reducing PA's waiting list
- The waiting list continues to negatively affect those who wait for services and their families, who in some cases are unable to work in order to care for the individuals waiting

IMPACT OF THE COVID-19 PANDEMIC
on Intellectual Disability/Autism Service Capacity

METHODOLOGY
In May 2021, Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities (PAR) surveyed its membership of providers of Intellectual Disability/Autism (ID/A) services to determine if there was a decrease in the number of individuals served between July 1, 2019 and May 1, 2021. Respondents were asked to report only changes in the number of individuals with (ID/A) served, not changes in the number of hours provided. Seventy-three organizations responded to the survey.

RESULTS
The results showed that every service experienced a reduction in service capacity, ranging from three percent up to sixty-seven percent. The service capacity reduction in the ID/A system averaged 24% across these service types.

Service Type	Change in Number of Individuals Served from 2019 to 2021	% Change
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DISCUSSION
These results show a highly concerning trend toward a reduction in the capacity of providers to support individuals with ID/A. This is likely a conservative estimate of the total impact on service capacity as it only measures the number of individuals impacted, not whether the individuals served have experienced a reduction in the number of hours of services they receive. For example, multiple providers noted that while they are serving a similar number of individuals in 2021 compared to 2019, all of the individuals went from full-time services to part-time. These reductions are likely driven by program closures due to the pandemic and the reduced workforce as day service providers were forced to lay staff off and the Direct Support Professionals working in residential setting leaving due to high demand to work overtime, and low wages for high-contact/high-risk jobs. As services have slowly begun to reopen, many providers have been unable to attract staff back or to get new staff in the door.

RECOMMENDATION
It is critical that Pennsylvania provides $540 million in funding now for COVID-19 relief. It is also imperative to address long-term systemic issues including the workforce crisis and the waiting list for services.

| Report Date: JUNE 17, 2021

Pennsylvania Advocates and Resources
for Autism and Intellectual Disabilities

4 Lemoyne Drive, Suite 203, Lemoyne, PA 17043
Ph: (717) 236-2374 | Email: par@par.net

FISCAL IMPACT OF THE COVID-19 PANDEMIC
on Intellectual Disability/Autism Providers

As the pandemic has continued, so has the devastating impact on people with intellectual disability and autism (ID/A) and ID/A providers. Studies have shown that individuals with ID/A are more than twice as likely to die from COVID-19 and staff turnover is up 80%. Providers have scrambled to fill shifts while trying to find Personal Protective Equipment (PPE) to keep individuals and staff safe during the pandemic. Reopening services is a new challenge with staffing, space, safety, and sanitation requirements. In addition to these challenges, providers of ID/A services have taken an enormous financial hit throughout the pandemic. The data below shows the extent of the alarming fiscal impact of the COVID-19 pandemic on Pennsylvania ID/A providers.

METHODS

On April 28, 2021, PAR surveyed its membership to assess if the COVID-19 pandemic caused loss of revenue and increased costs for ID/A provider organizations. Respondents were then asked to identify what strategies and resources they used to cope with any loss of revenue or increased costs.

RESULTS

71 provider organizations responded to the survey representing about $1.6 Billion in ID/A services. 94% indicated that they experienced loss of revenue and 97% experienced increased costs due to the COVID-19 pandemic. The methods providers utilized to cope with this loss of revenue and increased costs are outlined below.

Methods to Deal with Loss of Revenue	Count	%	Methods to Deal with Increased Costs	Count	%
Utilized COVID-19 relief funding	64	90%	Utilized COVID-19 relief funding	62	87%
Accessed reserves	38	54%	Accessed reserves	42	59%
Used exempt* staff to cover DSP shifts	32	45%	Used exempt* staff to cover DSP shifts	25	35%
Laid off staff	26	37%	Laid off staff	19	27%
Accessed line of credit/took out a loan	15	21%	Accessed line of credit/took out a loan	16	23%
Other	18	25%	Other	13	18%

Other methods utilized included: redistributing remaining staff to different services, reducing capacity of services, decreasing costs whenever possible, and asking for donations.

CONCLUSION

These results highlight the enormous financial hit ID/A providers have experienced throughout the COVID-19 pandemic. Providers have been creative during these desperate times, using multiple strategies to continue critical services to people with ID/A. Providers using management staff to cover DSP shifts has led to management staff turnover as they are working excessive hours with no overtime pay. COVID-19 relief funding is close to exhausted in some cases and used up in others. Providers simply do not have sufficient financial resources to continue supporting individuals with ID/A to live safe, healthy, and fulfilling lives.

PAR is strongly advocating for $540 Million in COVID-19 relief funding to ensure that ID/A providers can stay afloat, in addition to recruiting and retaining enough staff to provide critical services to individuals with ID/A.

**Exempt refers to employees who are salary and do not receive overtime*

Report Date: JUNE 17, 2021

Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities
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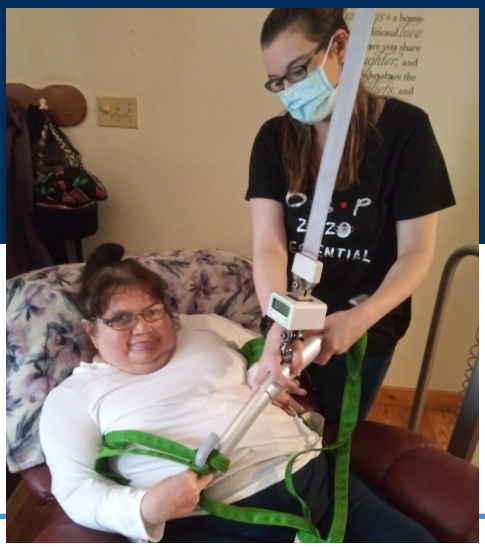
Ph: (717) 236-2374 | Email: par@par.net

IMPACT OF COVID-19
On ID/A Providers in PA



ANCOR (American Network of Community Options and Resources) surveyed ID/A (intellectual disability/autism) Providers across the Commonwealth of Pennsylvania to gather data to analyze the impact that the COVID-19 pandemic has had on those providers. The findings show a significant negative financial impact on Pennsylvanian organizations that provide ID/A services.

METHODOLOGY OF SURVEY DATA AND FINDINGS:

This information is based on data polled from 69 provider respondents from Pennsylvania, as well as information gathered by PAR, ODP (PA Office of Developmental Programs) and PROMISe (PA Medicaid claims data). **The respondents represent $1.853 billion in ID/A services and employ 31,671 DSPs (Direct Support Professionals).**

RESULTS

- Loss of annual revenue due to state-mandated/Coronavirus-driven service closures on average: 25.3% of annual ID/A revenue
- Increase costs due to COVID-19 on average: 2.6% of annual ID/A revenue
- Financial impact on providers of lost revenue and increased cost on average: 27.9% of annual revenue
- Cash on hand per provider per month on average: 2.9 days
- Pennsylvania ID/A providers need $89,446,794 per month in COVID-19 relief funding

ASSUMPTIONS

- This report is a system-wide analysis and uses an equitable distribution of impact across all ID/A service lines in Pennsylvania.
- The experiences of providers vary, anecdotally based on the number of people they support who have tested positive for COVID-19, the impact of COVID-19 in their geographic area, and their mix of services. For example, the recent experience of providers in Southeastern PA where the COVID-19 virus has been most aggressive, suggests that provider costs may have increased significantly since the survey. Providers in Southeastern PA are experiencing a dramatic increase in the lack of DSPs caused by resignations, staff call-offs and physician-suggested self-isolation of staff.
- It will likely require a blend of state and federal relief to alleviate the financial burden brought on by the COVID-19 pandemic (state relief may come from federal relief to the state).
- CPS and day program losses of revenue were reduced by 75%.
- Individuals enrolled in HCBS and ICF-ID remain relatively constant throughout the pandemic.

RECOMMENDATION

50,000 Pennsylvanians with ID/A rely on providers for support in their lives. Many cannot survive without supports. If the community system is decimated, what will happen to them and their families?

- With less that 3 days of cash on hand, $89,446,794 per month in additional funding is required soon for all Pennsylvania ID/A providers to sustain critical operations through the COVID-19 pandemic.
- The distribution of COVID-19 relief funding should be differentially distributed based on impact across service lines.
- COVID-19 relief funding is needed retroactive to March 1, 2020 and to continue through August 31, 2020 or two months after the COVID-19 outbreak ceases, whichever is later.

Report Date: APRIL 30, 2020

MAX PAR Pennsylvania Advocacy and Resources for Autism and Intellectual Disability
RCPA Rehabilitation & Community Providers Association
The Alliance of Community Service Providers
The Arc Pennsylvania
The Provider Alliance — Sharing Ideas, Resources, and Purpose

EDITORIAL USA TODAY NETWORK – PENNSYLVANIA

Pa.'s most vulnerable need our help

Sandi Shaffer is desperate for the ivory tower set in Harrisburg to see what life is like for the tens of thousands of parents across the commonwealth who care for sons and daughters with intellectual disabilities and/or autism.

Sandi admits she'd like certain legislators to take her 25-year-old daughter Kate home for the day. Kate has intellectual and developmental delays, is nonverbal, has epilepsy and is on the autism spectrum. Maybe then the understanding she craves — and the help she needs — will come.

Maybe then the otherworldly distance — is it really only 200 miles? — between the rural backroads of Westmoreland County and the ritzy grandeur of Harrisburg's Capitol Rotunda can be bridged.

The community-based system that provides critical services for people with intellectual disabilities and autism is teetering on the verge of collapse, according to people on the ground who met with a USA Today Network — Pennsylvania editorial board last week.

Chronic underfunding of state-contracted non-profit organizations that provide direct support professionals for in-home care has stagnated wages for DSPs at an average of $14.38 per hour. That's appalling given that

See EDITORIAL, Page 12A

Sandi Shaffer, right, of Westmoreland County, has been unable to secure in-home care for her daughter, Kate Shaffer, 25, who is nonverbal and requires around-the-clock support. CONTRIBUTED PHOTO

ILLUSTRATION BY LUIS SOLANO ORTEGA/USA TODAY NETWORK; AND GETTY IMAGES

The Least of These: A hidden crisis

THE EDITORIAL BOARD
Pittsburgh Post-Gazette

JAN 16, 2022 | 6:00 AM

First in an occasional series about the crisis in Pennsylvania's services for people with intellectual disabilities and autism.

Sandi Shaffer lost her house because her daughter is disabled.

That sentence should make every politician in Pennsylvania sick. It represents a catastrophic failure of the commonwealth's services for those with intellectual disabilities and autism (ID/A) — services it is bound by law, not to mention basic human dignity, to provide.

The catastrophe is ongoing, and worsening every day.

According to the state, there are about 58,000 people with ID/A currently receiving services from direct support professionals (DSPs) across Pennsylvania. Some of these people only require infrequent check-ins with their care providers, but others — about 12,000 — are getting intensive support in the day-to-day business of staying safe, clean and healthy.

But due to chronic underfunding, exacerbated by the coronavirus pandemic, 6,500 Pennsylvanians with ID/A have lost services in the past 18 months. And 12,000 are on a waiting list — an interminable queue from hell that seems, to families who are on it, like an elaborate and cruel joke.

Of those on that eternal list, 5,000 have an emergency need. But there are no DSPs to care for them.

That's where Ms. Shaffer and her daughter, Kate, find themselves. Kate, who is non-verbal and requires 24/7 supervision, graduated from the Children's Institute of Pittsburgh in 2017. She has been on a waiting list for a state-funded DSP for 16 years.

Ms. Shaffer lost her full-time job because she couldn't be in two places — at work and with her daughter — at once. She couldn't keep up on her mortgage. She now rents in Westmoreland County, holds down two part-time jobs, cobbles together care for Kate during the hours she can't be present and cares for Kate when she is present — all while also caring for her elderly mother.

This is a scandal. It is a violation of every principle of dignity and equality and justice that is written in law, and on the human heart.

Across the state, thousands of other families have been driven to despair and financial ruin by the state's inability to provide the care their loved ones are entitled to.

ID/A support providers and advocates are asking for an extra $136 million to be allotted for the state's care system in Gov. Tom Wolf's budget. That is an increase from $405 million to $541 million, and would be enough to stabilize the system. Due to federal matching funds, only $65 million would need to come from state dollars.

They are also asking for pay equity between care workers at state institutions and community-based DSPs, who are paid far less, a topic we will take up in the next installment of this series.

In terms of Pennsylvania's finances, $65 million is not a huge amount of money. It's less than 0.2% of this year's $40 billion budget, or 2.3% of the $2.8 billion "rainy day fund" socked away by the Republican-led Legislature. Further, the Wolf administration is projecting a substantial surplus this year.

The first obligation of a decent society is to care for those who cannot care for themselves. And so stabilizing Pennsylvania's care system for those with intellectual disabilities and autism should be the first thing Mr. Wolf and the Legislature do with the funds at their disposal.

It's the least they can do for the least of these, our brothers and sisters who depend on the care of others for their very lives.

First Published January 16, 2022, 6:00am

Editorial Roundup: Pennsylvania
By The Associated Press
Mar 9, 2022

USA Today Network - Pennsylvania. March 3, 2022.

Editorial: PA can — and must — stop the collapse of its disability system

Sandi Shaffer is desperate for the ivory tower set in Harrisburg to see what life is like for the tens of thousands of parents across the commonwealth who care for sons and daughters with intellectual disabilities and/or autism.

Sandi admits she'd like certain legislators to take her 25-year-old daughter Kate home for the day. Kate has intellectual and developmental delays, is nonverbal, has epilepsy and is on the autism spectrum. Maybe then the understanding she craves — and the help she needs — will come.

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The community-based system that provides critical services for people with intellectual disabilities and autism is teetering on the verge of collapse, according to people on the ground who met with a USA Today Network — Pennsylvania editorial board last week.

Chronic underfunding of state-contracted non-profit organizations that provide direct support professionals for in-home care has stagnated wages for DSPs at an average of $14.38 per hour. That's appalling given that DSPs administer medications, build behavioral support plans, manage mental health crises, work with medically fragile individuals, hold current CPR and first aid certifications and stay on top of the mountain of paperwork that comes with being ultimately answerable to Pennsylvania's Department of Human Services.

We ask DSPs to do all that for less than a motivated teenager can earn at Chick-fil-A and then, to add insult to injury, the state pays DSPs working in its facilities an average of $18.66 per hour.

It's no wonder the thousand or so non-profits the state contracts to provide services under the Home and Community-Based Waiver through the state's Medicaid program say they aren't able to retain good DSPs.

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This isn't a new problem, but increased demand for the services DSPs provide in a post-COVID world has triggered a full-blown crisis in the ID/A — intellectual disability and autism — world, where an estimated 12,000 Pennsylvania families sit on waiting lists for care.

Let's be clear: These are not families looking for a handout so they can spend more time living their best life.

Without a DSP to care for Kate, Sandi Shaffer has had to give up a full-time job, downsize from her house to a rental property and tap her retirement fund just to make ends meet. She now works part-time at a wellness center with flexible hours where she can build her schedule around the family members who pitch in to care for Kate.

Still, she sees her daughter regressing. Kate, who is very social, is home all day and night. She enjoys watching what's happening outside in the wooded area around the home but "she's almost becoming agoraphobic", says Sandi, who pulls no punches when she says Kate has "gotten lazy". They attend church on Saturday nights. They sit way in the back. Occasionally, they go to Target.

Except for when Sandi is at her job, she and Kate are together, even in the middle of the night. Kate's not much for sleeping.

Like all stories in the ID/A community, Sandi and Kate's is unique, but they aren't alone in feeling overwhelmed, exhausted and forgotten by the system.

Linda Smith, of Adams County, is her 38-year-old son Derrick Hemler's full-time caregiver. Derrick has Down syndrome. When he was in his mid-20s, he arrested during a 2010 surgical procedure and the lack of oxygen to his brain further compromised its functions. In 2012, his father died. He couldn't process the loss. When COVID hit, he lost access to programs that took him out of the home.

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The sum total of all that trauma was a schizoaffective disorder diagnosis. He has an imaginary family based on characters in a PS4 video game. He also has obsessive compulsive disorder, diabetes, a thyroid issue and is obese.

When COVID hit, Linda quit her 18-year job at a scrap metal recycling plant. Now she spends all her time with Derrick. The two of them live alone. Derrick also has a touch of agoraphobia. He prefers to stay in his room where he feels safe. Getting him to leave home is extremely difficult for Linda. Even when they venture out for his favorite treat — soft pretzels and frozen Cokes — he waits for her in the car.

Linda has help from 9 a.m. to 4 p.m. on Thursdays. She crams a week's worth of errands into that time — visiting her elderly mother, buying groceries, taking care of doctors' appointments and other stops. Some Thursdays she's booked so tightly that she gets lunch while out, but has to eat it while she drives.

Linda and Sandi aren't looking for sympathy or, worse, pity. They're looking for a promise of bold action from Governor Wolf when he gives his budget address on Tuesday.

Their lives, their children's lives, and the lives of thousands of Pennsylvania families would be enriched beyond measure by the presence of a DSP. And, unlike many problems bandied about in Harrisburg, this one has a relatively simple solution.

On Tuesday, Wolf must promise to fund the program, not at the proposed $405 million, but at $541 million. Advocates say that additional $136 million would allow state-contracted agencies to raise community-based DSPs' wages into the neighborhood of their counterparts in state facilities. That, they say, would improve employee retention and allow the agencies to hire additional staff needed to get help to the families on these waiting lists.

The money is there. Pennsylvania would only be responsible for $65 million, thanks to a federal government match. As for the rest, Pennsylvania ended last year with a

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budget surplus and state treasury receipts continue to outperform expectations. The commonwealth also has billions in federal pandemic-related stimulus money on hand.

A DSP working with Kate and Derrick for, say, 10 hours a day five days a week, would be the ultimate game-changer for them and their mothers. We believe that a dedicated — and fairly compensated — DSP could give Kate and Derrick the socialization they need, get them out of their homes and halt the regression they've experienced in the last 18 months.

As for their mothers, Sandi says having a DSP would give her a chance to get back to full-time work in a field that helps others in need — she formerly held a crisis intervention psychology position — while beginning the work of rebuilding her savings.

Linda admitted, almost reluctantly, that, while she loves Derrick and is committed to taking care of him, she does miss certain activities and ways to engage in various forms of self-care.

Linda says she'd like to go to Bingo or have lunch with a friend now and then rather than eating it in her car — "I have the same isolation as him", she says.
While we can't send Sandi's daughter Kate home with our legislators for the day, we're confident that we don't have to for them to see that parents like Linda and Sandi aren't asking for the moon and the stars here.

They're asking for something that will give them the opportunity to work, to earn a living, to provide for their families and to vastly improve their children's quality of life. And that the dedicated DSPs that give them the chance to do those things get a living wage in return.

The state can make this happen. It needs to make this happen.

EQUAL PAY FOR EQUAL WORK

AVERAGE WAGES AT STATE CENTERS ARE NOW $4.90 MORE PER HOUR THAN COMMUNITY DSPs

When the Commonwealth Experienced Staffing Problems, the Department of Human Services Simply Increased Wages.

	AVERAGE HOURLY WAGE		
	STATE CENTERS	COMMUNITY DSPs	WAGE DIFFERENCE
JUNE 1, 2021	$ 18.66	$ 14.38	$ 4.28
OCTOBER 1, 2021	$ 19.13	$ 14.38	$ 4.75
JANUARY 1, 2022	$ 19.28	$ 14.38	$ 4.90

STATE CENTERS NOW PAY RESIDENTIAL SERVICES AIDES $17.48 TO $24.19 PER HOUR

Source: Commonwealth of PA, www.governmentjobs.com

- The community ID/A system is at **SEVERE RISK OF COLLAPSING** because there are not enough DSPs to provide the supports and services needed by 58,000 Pennsylvanians.
- **MORE THAN 6,500** Pennsylvanians lost ID/A Services since the onset of the pandemic Pandemic.
- People with ID/A and their Families are suffering **PHYSICALLY**, **EMOTIONALLY**, and **FINANCIALLY**.
- The Governor's proposed budget **FALLS SHORT** of the investment needed to establish rates that will increase the average wages of community DSPs to the same level as state-employed aides.
- An additional $65 million[1] in state funds (which will be matched with $71 million) is needed to **AVOID COLLAPSE** of the community ID/A system.

[1] *When added to the line item for Intellectual Disabilities - Community Waiver Program, the $136 million in combined state and federal funds will move the average wage for community DSPs to $18.66 an hour.*

The Provider Alliance
SHARING IDEAS, RESOURCES, AND PURPOSE

Executive Summary
Proposed Fee Schedule Rates
for Intellectual Disability and Adult Autism Waiver Services

In response to proposed rates for Intellectual Disability and Autism Services (ID/A) published in the Pennsylvania Bulletin on January 1, 2022 from The Department of Human Services (DHS), The Provider Alliance (TPA) submitted its comment letter on January 18, 2022. Key arguments are summarized as follows:

There is no Standard Occupational Classification (SOC) code for Direct Support Professionals (DSPs) within the U.S. Department of Labor, Bureau of Labor Statistics (BLS). Therefore, DHS uses a combination of other SOC codes in its rate-setting methodology. Had DHS consistently applied its methodology from prior rate development, wage growth captured in fee schedule rates would be 18.2%.

Occupation	Occupational Title	Published BLS Data			
Code (SOC)		May 2015	May 2020	Pct. Increase	Average
21-1015	Rehabilitation Counselors	$ 18.56	$ 20.52	10.56%	18.20%
21-1093	Social and Human Service Assistants	$ 14.75	$ 17.09	15.86%	
31-1011	Home Health Aides	$ 10.58	$ 12.75	20.51%	
39-9021	Personal Care Aides	$ 10.65	$ 12.75	19.72%	
39-9041	Residential Advisors	$ 12.54	$ 15.59	24.32%	

Note: Including benefit and overtime costs based solely on the additional wages, this factor becomes 22.13%

Pennsylvania regulation and provisions stipulated within Home and Community Based Services (HCBS) Medicaid waivers require a market-based approach that should include trending beyond the most recently published BLS data from May 2020, as well as future cost projections.

Occupation	Occupational Title	Published BLS Data		BLS + CPI-U		
Code (SOC)		May 2015	May 2020	Dec 2021	Pct. Increase	Avg. Increase
21-1015	Rehabilitation Counselors	$ 18.56	$ 20.52	$ 22.31	20.22%	28.53%
21-1093	Social and Human Service Assistants	$ 14.75	$ 17.09	$ 18.58	25.99%	
31-1011	Home Health Aides	$ 10.58	$ 12.75	$ 13.86	31.04%	
39-9021	Personal Care Aides	$ 10.65	$ 12.75	$ 13.86	30.18%	
39-9041	Residential Advisors	$ 12.54	$ 15.59	$ 16.95	35.19%	

Note: Including benefit and overtime costs based solely on the additional wages, this factor becomes 34.7%.

Converting data from table 1 above into the percentage fee increase to fund compensation, a minimum rate increase of 15.43% is needed. DHS has invested only 10.5% into the fee schedule, which has not been increased since 2017. **This difference represents an additional shortfall of over $184 million**.

- DSP-equivalent positions at Pennsylvania State Centers earn on average $18.66 per hour versus $14.38 paid to community DSPs, a difference of 30%. State Center workers were guaranteed seven pay raises over the four-year period spanning 2019-2023.
- Community ID/A services averaged a 27% staff vacancy factor and 40-60% turnover rates in based on provider survey results from September 2021.
- The TPA Equal Pay for Equal Work campaign has consistently requested a total investment of $541 million into ID/A fee schedule rates to establish parity with the average wage at PA State Centers.
- TPA supports the application of a nationally-recognized annually-applied market index, as reflected in PA House Bill 92.

Given the $405 million proposed investment into the recently enacted fee schedule, another $136 million is needed to achieve Equal Pay for Equal Work. At anticipated federal matching levels for fiscal year 2022-23, this would require an additional $65 million in state dollars.

Paying care workers fairly

THE EDITORIAL BOARD
Pittsburgh Post-Gazette

FEB 3, 2022 | 12:00 AM

Workers who care for Pennsylvanians with intellectual disabilities and autism (ID/A) are paid different wages, depending on where they provide their services.

It's an inequality that has contributed to the serious instability of the state's system of care for people with ID/A. If it isn't fixed, the system may simply collapse.

People with ID/A in Pennsylvania receive services in one of two settings: either in state-owned institutions where they live full-time, or in community settings, such as with their families or with one another in shared residences.

Most advocates and families strongly prefer community-based care, where people with ID/A can experience regular social interactions and experiences, as opposed to the more regimented life in the centers.

In fact, the Wolf administration has already closed one state facility, and advocates say that two others may be closing soon.

Despite this clear preference, care workers in Pennsylvania's state centers are paid nearly 30% more than their community-based counterparts. And no matter where they work, all direct service providers (DSPs) are underpaid.

Right now, state center care workers are paid $18.66 per hour, while community-based DSPs get a measly $14.38. With the rise in market-based hourly wages during the pandemic, community-based care providers are now competing with restaurants for workers.

That $14.38 also hasn't changed in years, while state-center DSPs receive small but helpful annual raises. And because it's the state Medicaid reimbursement rate, it's the very most they can pay: There's no opportunity to earn more for excellent work, unless they are hired for one of the few management roles in these lean, cash-strapped organizations.

As a result, providers are struggling to attract the kind of compassionate, dedicated workers they need to serve often difficult clients. Many people with ID/A who receive these services are non-verbal, or can become aggressive when confused. Caring for them requires sensitivity, a tolerance for risk and a radical openness to friendship with someone so different, but who desires to be loved just as much as anybody else.

It is work that is worth much more than $14.38 an hour.

State Rep. Dan Miller, D-Mt. Lebanon, is known as a champion for people with ID/A. He tells us that he's looking for a "holistic solution" to the problems in the state's care system — but his House Bill 92 is a start. HB 92 wouldn't rectify the pay equity problem between state centers and community-based DSPs, but it would index all DSP wages to inflation, giving them a much needed raise.

This is promising, but we urge the Legislature to take the next step and mandate pay equity. There are complexities, such as the fact that state-center DSPs are unionized state employees and community-based DSPs are not, but the latter shouldn't need a union to force the legislature to do the right thing and pay them fairly.

We agree with Mr. Miller that there is a real opportunity for bipartisan action on this crucial issue. Caring for the least of these is a core duty of decent government that everyone should be able to agree about — and paying care workers well and fairly is essential to fulfilling that duty.

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Understanding the value of DIRECT SUPPORT PROFESSIONALS

"How society treats its disabled is the true measure of a civilization" – Chen Guangcheng

Direct Support Professionals (DSP) support individuals with intellectual disability or autism (ID/A). At their core, the DSP's job is to provide life sustaining support to individuals with ID/A and help them live independent and meaningful lives in their homes and communities.

DSPs' positions include a unique combination of tasks and requirements that are sometimes outside of the awareness of the general public and are often undervalued. DSPs wear many hats throughout the day to ensure the overall wellbeing of the individuals that they support (see Chart A: Common Tasks). DSPs often work autonomously without supervisors or coworkers nearby and shoulder a tremendous amount of responsibility for the health, safety, and wellbeing of the individuals they support.

DSPs are not officially recognized in the Bureau of Labor Statistics' Standard Occupational Classifications (SOC), which is just one aspect of the systemic undervaluing of the DSP. Providers of ID/A services are currently facing a crisis in finding DSPs and retaining the best ones, who often are forced to leave to find higher pay and easier job duties elsewhere. State governments and the federal government control the funding for ID/A services. Providers are price-takers and not price-setters and can only pay DSPs within the funding limitations imposed on them by the government.

To help address the systemic undervaluing of the DSP and the workforce crisis, we need to understand how critical the DSP is in the life of a person with ID/A and how complex, nuanced, and skilled their jobs really are.

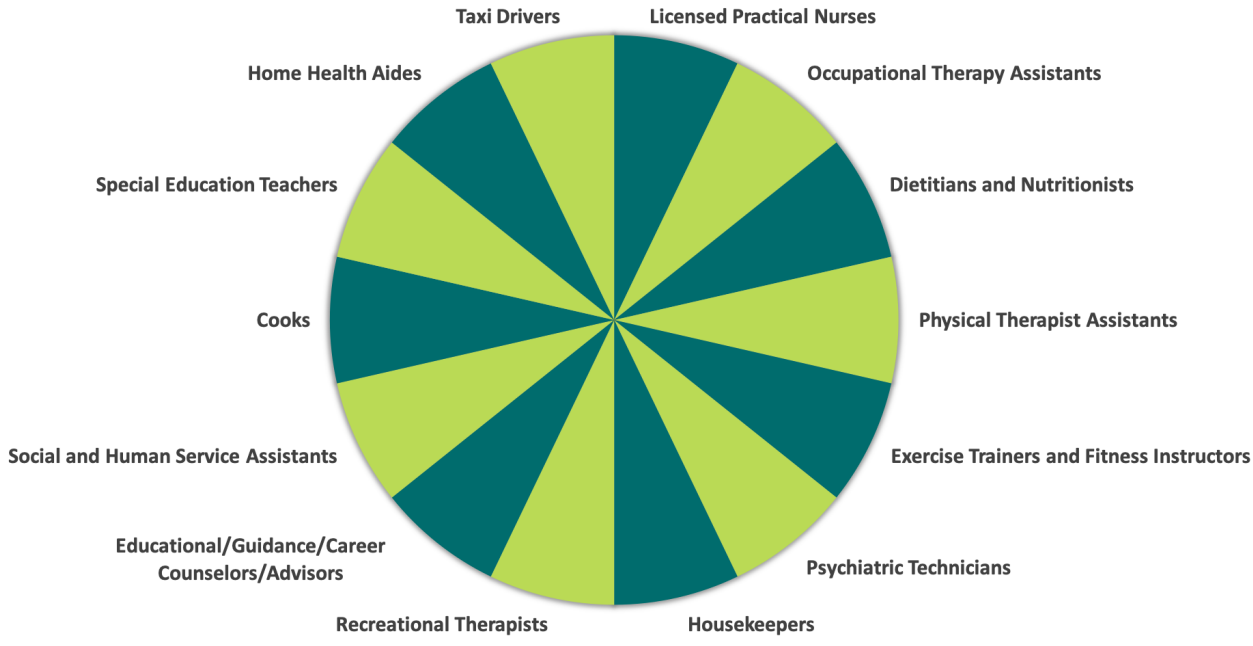
> *"Direct Support Professionals (DSPs) wear many hats… We assist with personal care, medication, and exercise. We are often responsible for providing medical care, writing detailed documents, and completing assessments. The truth is, that instead of focusing on a person's deficit and needs… we DSPs see the person we support as a person first. It is our job to listen to that person. We see their strengths and gifts. We support their contributions. When someone asks, "What keeps you working as a DSP?", I answer that it is an honor. Every day I have a chance to make a difference in the lives of people. In that way, no other job can compare."* **- Mary Frank, DSP-III at Community Connections, Inc., SD (Frontline Initiatives, 2020)**
>
> *"Realizing that the service that I provide is the service that I would want to receive, if I needed it, keeps me on task as a DSP daily… Being successful and highly competent as a DSP requires complex and varied skills leading to a succession of small victories, small hurdles and challenges that at some point becomes a life of possibilities. The people that I support have many stories of when it didn't work out, but to be a part of the memories when it worked out is a magical thing that completely fills me up day to day, and it comes with a responsibility that I don't take lightly."* **- Antonio McCall, DSP at SPIN, Inc., PA**
>
> *How DSPs talk about our job is important. We need to emphasize that direct support is a career that requires respect. This affects how others view our profession. I am a DSP and I take pride in that. It is a humble pride that allows me the humility to grow and improve my skills. I hope you too take pride in your job."* **- Skylar Smith, DSP-I at Black Hills Works, SD (Frontline Initiatives, 2020)**

CHART A: Common DSP Tasks, Occupational Roles, and Common Required Annual Training

Teaching new skills to increase independence, including instruction on assistive technology, public transportation, forming natural supports
Administering medications, including tube feeding and injections
Assisting in assessing needs, connecting individuals with their communities, ensuring basic needs are met
Guiding career exploration, supporting employment and relationship goals, teaching money management, teaching social skills
Grocery shopping, preparing food, teaching cooking skills
Transporting individuals to employment, shopping, entertainment, and social activities
Teaching and assisting individuals to gain/maintain physical abilities that increase/maintain independence such as strength building for walking, grasping, and hand-eye coordination
Cleaning house, light maintenance
Ensuring prescribed food consistency to prevent choking, ensuring nutritional needs of individual are met, including avoiding allergies, counting carbohydrates and calories, assisting in menu creation
Assisting with ordinary activities of daily life like bathing, eating, dressing
Planning and coordinating recreational activities such as sports, social activities, crafts, concerts
Monitoring and supporting physical and emotional well-being, provide appropriate behavior support and crisis intervention
Encouraging, instructing, and coordinating exercise activities to support fitness and well-being

Frank, M. (2020). *Increasing My Skills for Professional Practice Through the E-badge Academy*. Retrieved November 02, 2020 | Smith, S. (2020). *How I Talk About Direct Support as a Profession*. Retrieved November 2, 2020

CHART B: The Role of a DSP Incorporates Tasks from Various Occupations



In order to safely and effectively carry out these many roles, DSPs complete an abundance of annual training requirements

Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities

COVID-19 Pandemic Impact on the Pennsylvania ID/A Workforce Crisis

Center for Disability Information

TECHNICAL REPORT 08-1
August 24, 2021

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The COVID-19 pandemic has magnified the long-standing workforce crisis in the Intellectual Disability/Autism (ID/A) profession. In Pennsylvania, the pre-pandemic vacancy rate for Direct Support Professionals (DSPs) approached 20%, and annual turnover was estimated to be approximately 32% (Spreat, 2019). The collective subjective impression of Pennsylvania providers is that this pre-existing crisis has worsened subsequent to the onset of the COVID-19 pandemic in 2020.

In an effort to verify and objectify these impressions, the Center for Disability Information set forth to collect data from Pennsylvania agencies that provide support and service to individuals who have intellectual disability. All members of Pennsylvania Advocates and Resources for Autism and Intellectual Disabilities (PAR), a provider association, were invited in July 2021 to participate in a survey regarding the workforce crisis. Participation in the survey was limited to those agencies that are funded for services by the Pennsylvania Office of Developmental Programs and that could provide data related to Office of Developmental Programs services separated from other services.

SAMPLE

The sample consisted of 74 Pennsylvania agencies that provide ID/A services and supports through the Office Developmental Programs Home and Community Based Services waiver, ICD/ID funding, or base funding. These 74 agencies employed over 17,000 DSPs. All regions of the Commonwealth were represented, and there was considerable variety in the size of organizations. Note that agencies responded only to those questions that pertained to the services they provide.

WAGES

The essence of the workforce crisis is that provider agencies are unable to hire a sufficient number of qualified individuals to work as DSPs (Spreat, 2021). The demand for such individuals appears to be far exceeding the available supply. Providers believe this workforce challenge was exacerbated by the pandemic and mitigated by the pandemic relief funding that providers received. Our sample of 74 Pennsylvania provider organizations employed 14,756 full time DSPs and 2,704 part time DSPs as of July 2021. The mean hourly wage for full time DSPs was $14.35. For part time DSPs, the hourly wage was $14.21. Overall, the mean hourly wage paid by respondents was $14.33. The mean starting wage for a full time DSP was $13.65 per hour.

In a pre-pandemic report issued by a provider consortium (Spreat, 2019), it was reported that the mean hourly wage for DSPs was $13.20. The current reported rate represents an increase of just over 8%, largely attributable to the governmental pandemic relief funding provided to providers. It is reasonable to suggest that pandemic relief funding was largely responsible for limiting the negative impact that the pandemic purportedly had on the ID/A workforce, and that the continuation of funding at current or higher levels is absolutely essential.

TURNOVER & VACANCIES

Turnover was estimated using the same formula as used by the Office of Developmental Programs. The formula is simply the number of individuals who separated from employment within a given time frame (typically one year) divided by the number of individuals working at a specific point in time. In this particular survey, respondents reported the number of DSPs who left within a three-month period (April through June 2021). This means that figures had to be multiplied by four in order to achieve the commonly accepted annualized rate of turnover.

There were 14,756 working full time DSPs, and 1,897 full time DSPs separated from their employment between 4/1/21 and 6/30/21. This translates to an annualized turnover rate of 51.4% for full time DSPs. There were 2,704 working part time DSPs, and 527 who separated from employment between 4/1/21 and 6/30/21. These figures comprise an annualized turnover rate of 78% for part time DSPs. Combining full time and part time DSPs, the aggregate annualized turnover rate was 55.5%, a figure that is consistent with Consortium's earlier reported (Consortium, 2020) rate of 56% and 75.6% higher than the reported pre-pandemic turnover rate (Spreat, 2018).

Vacancy rate is calculated by dividing the number of vacant (or empty) positions by the number of filled positions plus the number of vacant positions. There were 3,839 vacant full time DSP positions and 1,448 vacant part time DSP positions. These figures translate to a full time vacancy rate of 20.6% and a part time vacancy rate of 34.9%. The overall vacancy rate, combining full time and part time positions, was 23.2%. This index represents an increase of 19.6% over a pre-pandemic survey (Spreat, 2018). It should be recognized that these vacancy figures may underestimate the magnitude of the problem because a number of day programs have not yet returned to full operation, and many day program staff have been reassigned to work in residential positions.In addition, the survey did not include temporary vacancies such as family medical leave act, workers compensation, extended sick time due to COVID - which did result in operational vacancies and the need for additional staffing/overtime.

It is reasonable that these turnover and vacancy figures underestimate the magnitude of the workforce crisis because most respondents report a heavy reliance on both management staff and day program staff to work in DSP positions during the crisis. 89.9% of respondent agencies reported that they have had to require management staff to perform increased levels of direct support services because of staffing shortages, and 88.4% of agencies that operate day program services have assigned day program staff to residential areas. If a provider had to pay overtime to replace the 1,912 frontline managers working an average of 20 hours per week, overtime costs would be projected to increase to 22.3%. If one estimates that just 1/3 of the unused day program hours were devoted to residential direct support, the projected overtime costs would increase to 35.4%.

The vacancy and turnover problems are not limited to DSPs. Frontline management staff are currently experiencing a 35.6% annualized turnover rate and a 13.5% vacancy rate. While these values are less than those reported for Direct Support Professionals, both are higher than previously reported values for this level of management. In 2018, Spreat reported (Spreat, 2018) that frontline management turnover was 19.7% and vacancy rate was 9.2%. Current data represent increases of 80.7% in turnover and 46.7% in vacancies of frontline management staff.

RECRUITMENT

Most respondents (97.2%) reported that hiring Direct Support Professionals had become “more difficult” or “much more difficult” over the previous six months. Despite the fact that 10,476 individuals had applied for DSP positions from 4/1/21 through 6/30/21, 97.2% of respondents said that the number of applicants was “not quite enough” or “grossly inadequate". Given that only 12.6% of the applicants were actually hired into DSP positions and only 75% of those hired actually worked longer than 30 days, the conclusion of the inadequacy of an available DSP workforce seems justified. This means that only 9.4% of the applicants for a DSP position ended up working for more than 30 days. Given the reported turnover and vacancy rate in combination with the hiring shortfalls, one might reasonably predict the continuation of the workforce crisis unless supply and demand are somehow balanced.

The hire rate is certainly affected by individuals who are double counted by applying to several agencies, however, the low hire rate seems surprising given that 47.2% of the respondents reported that the workforce crisis had forced them to become less selective in their hiring practices. The survey yielded no data that would offer meaningful explanations of this outcome.

Respondents reported the use of a variety of incentive programs to attempt to increase applicants who are willing and qualified for Direct Support Professional positions. It is assumed that these programs were funded primarily by pandemic relief funding and will not likely be able to be continued without additional and permanent funding. The following actions were reported:

Increased starting DSP hourly wage by less than $1	27% of organizations
Increased starting DSP hourly wage by more than $1	50% of organizations
Offered signing bonus for new employees	54.1% of organizations
Rewarded current employees for referring applicants	79.7% of organizations
Decreased selectivity in hiring	45.9% of organizations

STAFFING SHIFTS

Ensuring that there are sufficient staff to ensure the safety of consumers has become an increasing challenge. Respondents reported that since 4/1/21, callouts have increased (61.8% of respondents) and use of overtime has increased (76.5% of respondents). Almost 90% of the respondents (89.9%) reported that they have increasingly had to rely on management staff to cover shifts due to an insufficient number of Direct Support Professionals. They reported that management staff are now typically working about 20 hours per week providing direct supports. It was noted that 63% of the agencies have had to rely on upper-level management to cover shifts.

During the period from 4/1/21 through 6/30/21, respondents reported that they paid DSPs for 7,097,592 hours at regular pay and 1,314,818 hours on overtime pay. This means that 15.6% of monetary compensation paid to DSPs was at an overtime rate. This does not include overtime that is associated with frontline managers and reallocation of staff from services with temporary diminished capacity. Approximately 76.5% of respondents reported that the use of overtime increased during this period. Increased callouts, typically resulting in additional overtime costs, were reported by 61.8% of respondents.

RESIDENTIAL SERVICES & SUPPORTS

Respondents were asked how many individuals they were supporting in residential homes in March 2020 and in June 2021. They reported that 7,125 individuals were served/supported in 2020 and 6,860 in 2021. This is a decline of 265 individuals and approximately 3.7%. Slightly over 20% (21.8%) of respondents reported that staffing problems had forced their organization to reduce residential census. Approximately 48% reported that they have placed a cap on residential admissions due to staffing, and 20 agencies (27% of the sample) reported that they closed at least one home between March 2020 and June of 2021. Seven organizations (9.5% of the sample) reported that they discharged individuals from residential supports because they could not get staffing. 84% of respondents indicated that staffing challenges would force them to decline an ODP request to open additional residential services because of staffing challenges.

DAY PROGRAM SERVICES

Day Program services were closed for a significant period of time during the height of the pandemic. Many day program services have only recently reopened, and several remain closed. Over 80% of the respondents (81.6%) reported that staffing challenges have led them to either delay or reduce the opening of day program services.

Because of the closing of day program services, a pre-pandemic date was selected with which to compare current offerings. In October 2019, the respondents provided day programming for 7,068 individuals. This figure now stands at 4,193, a reduction of 2,875 individuals and 40.7%. The units of services suggested an even larger decline, suggesting that people may be returning at reduced hours in day programming. The units of service in October 2019 were 2,423,140, and the comparable figure for June 2021 was 1,043,408. This is a 61.4% decrease.

It should be noted that 88.4% of respondents offering day program services reported that some percentage of their day program staff were assigned to residential program components. In a sense, the need for support in the residential areas has taken precedence over day program services.

IN-HOME & COMMUNITY SUPPORTS

Survey respondents who provide in-home and community supports billed for 556,424 units of service in October 2019. In June 2021, they billed for 431,788 units of service. This represents a decline of 22.4%. Over half of the respondents reported that they had a waiting list for in-home and community supports, with a total of 327 individuals on those waiting lists. Earlier Pennsylvania research (Consortium, 2020) reported that in-home and community supports had declined approximately 37% as a result of the pandemic.

OPERATIONS

As noted above, the current workforce crisis would appear to make most respondents reluctant to respond affirmatively to an ODP request to increase levels of direct support services. Respondents went on to note that approximately one half (50.7%) are actively pursuing downsizing in response to the workforce crisis. Over half (55.9%) of respondents reported that they have had to defer any expansion plans due to the workforce crisis.

CONCLUSION

The sample used for this report included providers employing about 1/3 of all DSPs in Pennsylvania. These mid-pandemic data present a troubling picture. Providers are unable to hire sufficient number of qualified DSPs to perform necessary support functions. Management staff are required to work direct care. While residential services are largely being maintained, both day program services and in-home supports and services have not returned to anywhere near pre-pandemic levels.

Providers are forced to reduce their service capacity but also to serve people with lower acuity.

The workforce crisis and current funding levels put providers in a position where they simply do not have the resources to accept new high acuity individuals until the workforce is stabilized. Some providers have implemented steps to reduce their capacity and acuity of individuals served to match their ability to staff programs. While this is one way to achieve a balance between supply and demand, it will create expanded waiting lists of people with ID/A.

The ID/A field remains in crisis and without additional continued support, it risks implosion. Continuation of funding at and above the relief funding will be essential to the survival of the Commonwealth's system of care for people with ID/A.

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APPENDIX

Full Time Direct Support Professionals

- 14,756 Full Time DSPs
- 3,839 Full Time DSP positions currently vacant
- 1,897 Full Time DSPs left between 4/1/21 and 6/30/21
- Turnover rate = (1,897*4)/14,756 = 51.4%
- Vacancy rate = 3,839/(3,839+14,756) = 20.6%
- Mean Hourly wage = $14.35
- Starting Hourly wage = $13.65

Part Time Direct Support Professionals

- 2,704 Part Time DSPs
- 1,448 Part Time positions current vacant
- 527 Part Time DSPs left between 4/1/21 and 6/30/21
- Turnover rate = (527*4)/2704 = 78.0%
- Vacancy rate = 1,448/(1,448+2,704) = 34.9%
- Mean Hourly wage = $14.21

Use of Overtime

- 6,187,314 DSP hours billed at regular pay from 4/1/21 through 6/30/21
- 1,314,818 DSP hours billed at overtime pay from 4/1/21 through 6/30/21
- 15.6% of all DSP hours were billed at the overtime rate
- Note: this analysis used only providers that listed billing for both regular and OT hours
- N=58

Applicants

- 10,476 applicants between 4/1/21 and 6/30/21 – 69 respondents
- 1,322 applicants were hired by the 69 respondents (12.6%)
- 1,020 applicants worked at least 30 days (75.9% of those hired)
- 97.7% of respondents reported that number of applicants was insufficient
- 97.2% of respondents reported that hiring DSPs has become more difficult over last 6 months
- Actions to increase number of applicants
    - 20 organizations raised hourly rate by less than $1
    - 37 organizations raised hourly rate by more than $1
    - 40 organizations offered a signing bonus
    - 59 organizations rewarded current employees for making referrals
    - 34 agencies decreased selectivity in their hiring
- 96.6% of organizations say securing staffing has become more difficult

Management Staff

- 1,912 Frontline Managers worked for 71 responding organizations
- 259 Frontline Manager positions were currently vacant
- 170 Frontline Managers left organization between 4/1/21 and 6/30/21
- Turnover Rate = (170*4)/1,912 = 35.6%
- Vacancy rate = 259/1,912 = 13.5%

Mean Training Hours Annually

- 36.0 hours for Direct Support Professionals
- 42.66 hours for Frontline Managers

Residential Services

- 7,125 individuals receiving residential services as of 3/1/2020
- 6,860 individuals receiving residential services as of 6/30/21
- 265 fewer individual receiving residential services
- Decrease of 3.7%
- 48% of responding agencies (n=25) have capped their admissions
- 37% of responding agencies (n=20) have closed at least 1 home since 3/1/2020
- 58 number of homes reported to have been closed
- 7 number of individuals discharged because of staffing shortages

Day Program Services

- 7,068 individuals receiving day services as of October 2019
- 4,193 individuals receiving day services as of June 2021
- 2,875 less individuals receiving day services currently
- 40.7% fewer individuals in day services
- 2,423,140 units of day services provided in October 2019
- 1,043,408 units of day services provided in June 2021
- 1,487,159 less units of day services provided
- 61.4% decrease in number of day service units provided
- 88.3% of respondents deploy day services staff to fill residential services void

In-Home & Community Supports

- 2,837 individuals receiving in-home and community supports October 2019
- 2,502 individuals receiving in-home and community supports June 2021
- 335 fewer individuals receiving in-home and community supports
- Decline of 11.8%
- 556,424 units of in-home and community supports billed in October 2019
- 431,788 units of in-home and community supports billed in June 2021
- 123,636 less units of in-home and community supports provided
- 22.4% decrease in units of in-home and community supports provided
- 53.5% of providers on in-home and community supports have a waiting list
- 327 individuals on these combined waiting lists

Management Operations

- 38 agencies (55.9%) deferred on expansion plans
- 34 agencies (50.7%) actively pursuing downsizing/rightsizing
- 61.8% of agencies report callouts have increased between 4/1/21 and 6/30/21
- 76.5% of agencies report overtime use has increased between 4/1/21 and 6/30/21
- 89.9% of agencies report increased requirement for management to work direct support
- 64.2% of agencies report that senior management has had to cover direct support

Overtime Assumptions

- 1,912 Frontline Managers work an average of 20 hours/week as DSPs; this is 240 hours over 3 months.
- 1,912 * 240 = 458,800 hours that would have been paid at overtime rates, if staffing permitted. Therefore, paid regular hours = 6,187,314; paid overtime hours = 1,314,818; and management hours = 458,800. Paid OT hours and management hours would equal 22.3% of total hours worked.
- 88.3% of day programs report deploying their staff to residential programs, in a sense, offsetting residential costs and keeping these employees working. In June 2021, day programs were billing 1,487,159 fewer hours than they billed pre-pandemic. Inclusion of just 1/3 of these offsetting day program hours suggests that if the positions could have been filled by DSPs, the overtime costs would approach 35.4%.

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(RESEARCH ARTICLE)

Check for updates

COVID-19 mortality rates for persons with intellectual and developmental disabilities

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Abstract

People with intellectual and developmental disabilities (IDD) appear to have an increased probability of death from COVID-19 once infected. We report infection and mortality rates for people with IDD compared to the general population of eight states at two time points during the COVID-19 pandemic. Note that these eight states contain approximately 1/3 of the population of the United States. These data suggest individuals with IDD are less likely to be infected with the COVID-19 virus (5.62%) than the general public (7.57%). However, while mortality rates for both groups have declined over time, people with IDD are over twice as likely (2.29) to die from the infection as members of the general public.

Keywords: Intellectual Disability; COVID; Mortality: Infection

1. Introduction

During the early phase of the COVID-19 pandemic, multiple sources reported that people with intellectual and developmental disabilities (IDD) appeared to have an increased probability of death from a COVID-19 infection. Studying a large California database, Landes, Turk, and Wong [1] reported that individuals with intellectual disability have a fatality rate (once infected) 2.8 times greater than the comparable rate for members of the general public. In a sample including roughly one-third of the United States population, Spreat, Cox, & Davis [2] reported a relatively similar factor of 1.8 times the rate of fatality for people with intellectual disability than the general public. Landes, Turk, Formica, McDonald, & Stevens [3]. reported that COVID-19 fatality rates in New York group homes for people with intellectual disability were 1.9 times higher than the rates experienced by members of the general public. A recent national study covering January 2019 through November 2020 [4] reported that people with intellectual disability were more likely to become infected with COVID-19, more likely to become hospitalized, and more likely to die from COVID-19 complications. The reported fatality rate was 5.9 times higher than that of the general public. It is likely that some of the variation in the reported fatality rates derives from sampling variations, but it is noteworthy that all published reports suggest that the COVID-19 fatality rate is markedly higher for people with IDD than it is for members of the general public. Researchers have advocated for the need for ongoing empirical research documenting disparities in COVID-19 effects for people with disabilities [5], and the early evidence outlined above indicates people with IDD are at critical risk for such disparities.

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At the time of this research, COVID-19 pandemic continued, with the number of infections and the number of deaths growing daily. Data collected by Johns Hopkins University [6] suggest the probability of death resulting from a COVID-19 infection for any individual has declined from almost 7% in Spring of 2020 to slightly less than 2% in early 2021. Over one year after the pandemic onset in the United States in March 2020, vaccines have become available, and the medical field has developed means with which to reduce the probability of death from a COVID-19 infection. As such, these changes warrant an examination of the impact of COVID-19 on the health of people with IDD at both early (May 2020) and later points (January 2021) in the pandemic to examine how early trends related to infection and fatality rates have changed over time.

2. Methods

2.1. Data Collection

Eight states had provided COVID-19 mortality and infection data for an earlier study involving people with IDD [2]. These eight state authorities provided data as of January 31, 2021 (plus or minus four days) to the researchers through IDD provider associations within each state. The eight states were California, Colorado, Indiana, Maryland, New Jersey, New York, Pennsylvania, and Virginia. Data regarding infection and mortality trends within each participating state were obtained from the website maintained by Johns Hopkins University [6].

2.2. Study Participants

The combined general population of these eight states was 107,722,117, or roughly 33% of the estimated population of the United States as of July 2019. As of January 31, 2021, these eight states supported/served 614,330 adults who have IDD. The number of individuals with IDD being supported varied somewhat across the two points in time, but the magnitude of these differences was not significant (0.5%).

2.3. Data Analysis

We compared rates of COVID-19 infection and fatality from COVID-19 once infected for people with IDD and the general public for the eight states in the sample at two separate points in time during the pandemic (May 2020 and January 2021).

3. Results

3.1. Infection Rate

As of May 31, 2020, 0.8% of the general public had been diagnosed with a COVID-19 infection. At this same time, 0.9% of the individuals with IDD had received positive diagnoses. With the spread of the COVID-19 virus and the passage of eight months, the percentage of the population that had been infected had grown substantially. Approximately 7.57% of the general public and 5.62% of the individuals with IDD had been infected with the COVID-19 virus.

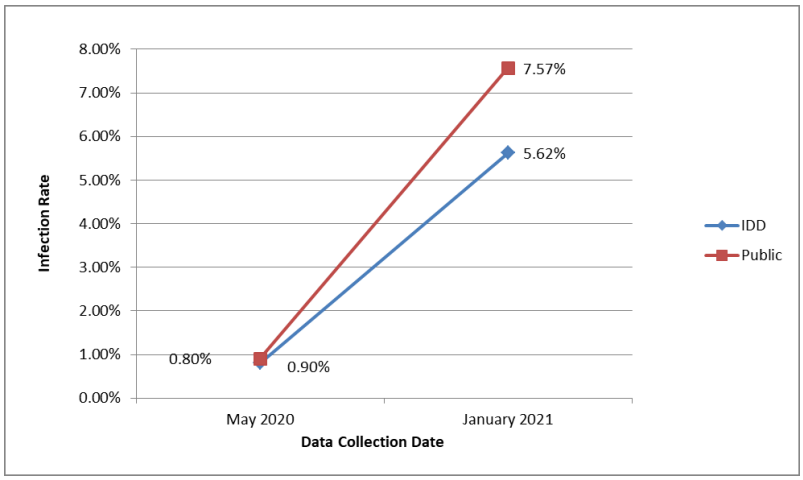

Figure 1 COVID-19 Infection Rates at Two Points in Time

Figure 1 presents the infection rates at the two points in time. The infection rate for individuals with IDD was .74 times the infection rate for the general population.

3.2. Fatality Rate

The recent data from January 2021 are encouraging in that the fatality rates for both those with IDD and members of the general public have fallen. Once infected, the probability of death from COVID-19 infection was less than 2% (1.94%) for members of the general public and under 5% (4.41%) for individuals with IDD. While the fatality rate has declined for both people with IDD (64%) and the general public (71%), the disproportionate impact on people with IDD has remained. Both members of the general public and people with IDD are now less likely to die once infected, but people with IDD are still at least twice as likely (2.29) to die from the infection as are members of the general public. The decline and the continuing disparity are represented in Figure 2.

Figure 2 Probability of Death Once Infected at Two Points in Time

4. Discussion

It is heartening to learn that the fatality rate for both people with IDD and members of the general public declined dramatically over the first eight months of the pandemic. The probability of death, once infected with COVID-19, overall declined over 70%. Despite this relatively positive outcome, it is noted that people with IDD appear to have retained an increased probability of COVID-19 death when compared with members of the general public.

It has been hypothesized that the increased fatality rate for people with IDD is largely a function of health issues that are commonly co-morbid with IDD. Turk and McDermott [7] noted that people with IDD tend to have a higher number of health issues than do members of the general public, and that the number of co-morbid conditions was a major predictor of COVID-19 fatality. Supporting this observation, researchers in Ireland reported, after reviewing records of 66 individuals with intellectual disability who died from COVID-19, that these individuals had high levels of epilepsy, dysphagia, mental illness, dementia, and tended to be overrepresented in lower functioning ranges of intellectual disability [8]. In discussing the increased COVID-19 fatality rate for people with Down Syndrome, Clift, Coupland, Keogh, Hemingway, & Hippisley-Cox [9]. reported that their analysis suggested that cardiovascular and pulmonary challenges were at least partially responsible for the increased mortality rate. Despite the credibility of the hypotheses regarding comorbid conditions, Gleason, Ross, Fossi, Blonsky, Tobias, & Stephens [4] noted that even when comorbid conditions were statistically controlled, the presence of intellectual disability was the largest predictor of negative outcome. Clearly, additional research is warranted regarding the impact of co-morbidity on COVID-19 related deaths.

It was also noted in the present study that individuals with IDD were slightly less likely to become infected by the COVID-19 virus, particularly at the second time point. The modest difference is perhaps attributable to the closing of many day programs, the general limitation on community-based activities. While subject to empirical verification, it may be that the IDD provider community, despite the regular rotation of staff into homes, was better able to implement COVID-19 mitigation strategies, such as masking and social separation than were members of the general public. It was early understood that people with intellectual and developmental disabilities were inherently at higher risk of poor COVID-

19 outcomes, confirmed by all early empirical evidence [1,2,3,4]. This finding is a very positive testament to the responsiveness of agencies to the pandemic, once resources became available for them to mitigate risks.

Limitations and Directions for Future Research

It should be noted that the collected data were not submitted to statistical analysis beyond simple reportage of summary figures. With a large sample such as was employed here, any observed difference would have achieved statistical significance. The issue must instead shift to the matter of practical significance. For example, the difference in infection rate in May 2020 achieved statistical significance in trial runs via chi-square analysis, but one must evaluate the real-world impact of the 0.1% difference. On the other hand, the roughly 2% difference noted in January 2021 suggests that almost 12,000 more individuals with IDD would have been infected with COVID-19 if matters were equal. And, based on the fatality data, we would estimate that of those individuals, over 500 would have died. We suggest additional research on a longitudinal basis would be helpful to discern the etiology for the increased mortality risk for people with IDD.

It must be recognized that this was a population-based study, incorporating data on people with and without IDD in eight states. Additionally, it is likely that many factors beyond the mere presence of IDD distinguish these two groups, and that factors other than the classification of IDD may explain the observed outcomes. For example, it is noted that people with intellectual disability tend to have slightly shorter life spans than the general public [10], so it is reasonable to suggest that age may be a distinguishing factor. An age matched cohort study would shed additional light on this question.

5. Conclusion

These data suggest that people with intellectual and developmental disabilities were 2.29 times more likely to die from a COVID-19 infection, but only .74 times as likely to become infected. Conjointly, consideration of both infection rate and mortality rate would suggest that people with IDD are roughly 1.7 times as likely to die from COVID-19 when mitigation strategies are employed. The point is that industry-wide mitigation efforts were more effective than general societal efforts, and this helped to offset some of the increased medical risk associated with the category of IDD.

It should be noted that there are hundreds of causes of IDD. Some of these are genetic syndromes, like Down syndrome, that may specifically place individuals at higher risk due to poorly understood, genetically-related mechanisms that are unique to the syndrome and do not apply to the rest of the IDD population. It is also likely that there are some high risk factors that are more common in the IDD population, compared to the neurotypical population. In order to be truly responsive to the needs of the IDD population, these observations suggests that next research steps should focus on the identification of major driving factors of susceptibility to COVID-19 infection and death.

Compliance with ethical standards

Acknowledgments

The authors thank and acknowledge the contribution of the eight IDD provider associations whose acquisition of data form their state authorities permitted this analysis.

Disclosure of conflict of interest

None of the authors report any conflict of interest in the conduct of this study. The study was not a funded project.

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Monthly Telehealth Regional Tracker, Nov. vs. Dec. 2021

Northeast: *CT, ME, MA, NH, NJ, NY, PA, RI, VT* | ***A Month-to-Month Comparison***

Top Five Procedure Codes by Utilization

In order from most to least common

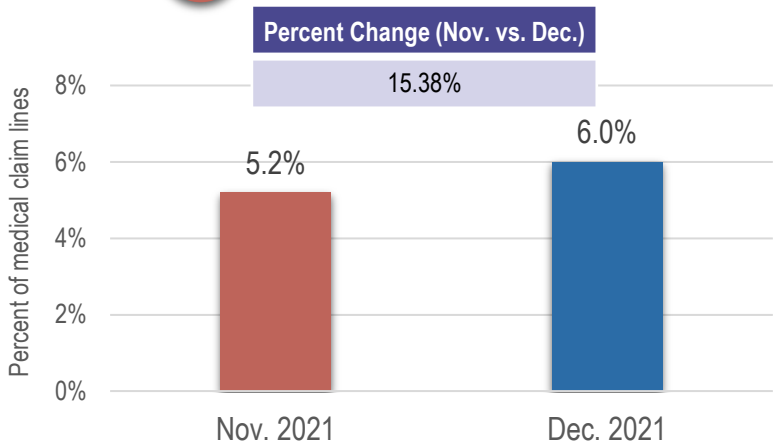
Nov. 2021

CPT®/HCPCS	DESCRIPTION
90837	PSYCHOTHERAPY, 60 MINUTES
90834	PSYCHOTHERAPY, 45 MINUTES
99213	ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 20-29 MINUTES
99214	ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 30-39 MINUTES
90833	PSYCHOTHERAPY PERFORMED WITH EVALUATION AND MANAGEMENT VISIT, 30 MINUTES

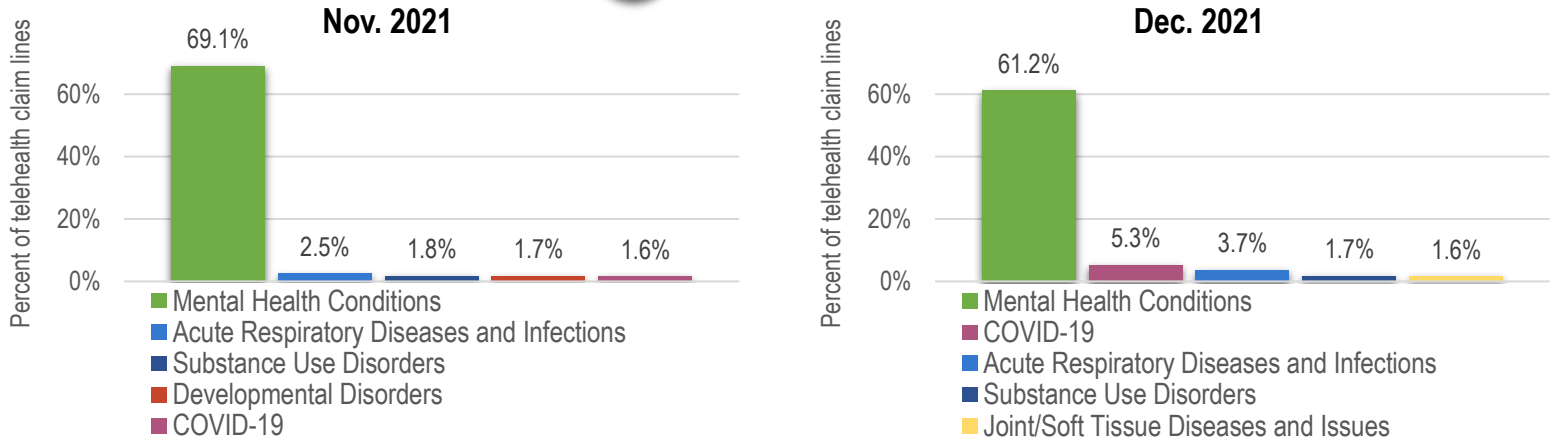
Dec. 2021

CPT®/HCPCS	DESCRIPTION
90837	PSYCHOTHERAPY, 60 MINUTES
99213	ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 20-29 MINUTES
90834	PSYCHOTHERAPY, 45 MINUTES
99214	ESTABLISHED PATIENT OUTPATIENT VISIT, TOTAL TIME 30-39 MINUTES
90833	PSYCHOTHERAPY PERFORMED WITH EVALUATION AND MANAGEMENT VISIT, 30 MINUTES

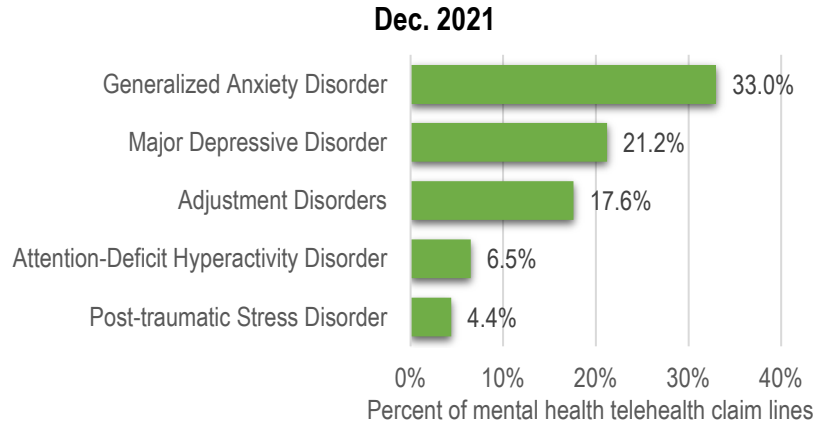
Volume of Claim Lines



Top Five Diagnoses



Top Mental Health Diagnoses, Dec. 2021



Source: FH NPIC® database of more than 36 billion privately billed medical and dental claim records from more than 70 contributors nationwide.

The Mental Health Safety Net Coalition

Alliance of Community Service Providers

Brook Glen Behavioral Hospital

Clarion Psychiatric Center

Conference of Allegheny Providers (CAP)

Fairmount Behavioral Health System

Family Training and Advocacy Center (FTAC)

Foundations Behavioral Health

Friends Hospital

Horsham Clinic

Keystone Center

Keystone National Alliance for the Mentally Ill (NAMI)

Lancaster Behavioral Health Hospital

MAX Association

Meadows Psychiatric Center

Mental Health Association of PA (MHA)

Pennsylvania Association of County Administrators of Mental Health and Developmental Services (PACA MH/DS)

Pennsylvania Mental Health Consumer Association (PMHCA)

Pennsylvania Psychiatric Leadership Council (PPLC)

Rehabilitation and Community Providers Association (RCPA)

The Roxbury Treatment Center

Treatment Advocacy Center

February 14, 2022

Dear Pennsylvania Legislators,

On behalf of the Mental Health Safety Net Coalition, we are writing to state the urgent need for the General Assembly to not only support the $36.6 million increase in funding for county mental health services in the Governor's proposed FY 2022/23 state budget, but also to add additional investments much needed in these critical behavioral health services.

As you know, the ongoing COVID-19 pandemic is creating an unprecedented constellation of challenges for our mental health system, including dramatic increases in the need for mental health services, significant health staff shortages, unprecedented changes in the labor market, increases in completed suicides, and heightened ongoing ravages of diseases of opioid addiction. Adequate funding for county mental health services is a crucial element of the Commonwealth's response to these shared challenges.

Importantly, the Governor's proposed increase will help offset the loss in purchasing power due to a decade of level funding. This money is critical to help counties get back to the effective level of resources they had 10 years ago, but it does not even begin to address all the gaps in our mental health system or surging demand for mental health services as we enter the third year of the global pandemic.

In addition to gap-filling services like supportive housing and residential services, county mental health funds are crucial for access to treatment in the counties' role as provider of last resort. There are uninsured individuals; there are individuals who have reached their private insurance limit that need services; and there are county community mental health services that are not available under private health plans.

As you may recall from our prior Coalition communications, the failure to invest in these mental health services is causing even greater state expenditures in other services, including Medicaid, corrections, and criminal justice, resulting in human suffering. As we recently shared in a multitude of preventable tragedies, this has threatened the safety of communities across the Commonwealth.

We are respectfully requesting the General Assembly's assistance with addressing this unfolding crisis in county community mental health services. These services require sustained investment of state funds on an ongoing, multi-year basis — and equally important consideration should be given to appropriate, one-time-only investments of ARPA funds to cover the capital costs of supportive housing and other residential services.

After more than a decade of level funding, we urge you to consider the $36.6 million proposed by the Governor for FY 2022/23 as the starting point for a realistic examination of the need for increased funding for county mental health services.

Sincerely,

The Coalition of the Mental Health Safety Net

PROVIDER QUICK TIPS

Telemedicine Guidelines Related to COVID-19

On March 6, 2020, Governor Wolf issued an emergency disaster declaration in response to the presence of the COVID-19 (coronavirus) in Pennsylvania. Pursuant to this disaster declaration, the Office of Medical Assistance Programs (OMAP) is issuing this guidance to advise providers that telemedicine may be used to provide services to Medicaid fee-for-service beneficiaries and Physical HealthChoices members. For questions related to a Physical HealthChoices Managed Care Organization's (MCO) coverage of telemedicine services, contact the MCO's provider services hotline directly.

COVID-19 is a communicable disease and some beneficiaries may prefer to receive health care services using telehealth instead of in-person. Telehealth is two-way, real time interactive communication between the patient and the doctor or other practitioner. There is no requirement for a physician or other healthcare professional to be physically present at the originating site, where the member is located. Telemedicine services may be provided by any means that allows for two-way, real-time interactive communication, such as through audio-video conferencing hosted by a secure mobile application.

On May 23, 2012, OMAP issued MA Bulletin 09-12-31 *et al*, *Consultations Performed Using Telemedicine*, which expressed the OMAP's preference for face-to-face consultations whenever possible but did provide instructions regarding the situations in which telemedicine services may be rendered to a fee-for-service beneficiary. The ability to provide telemedicine services, which were defined as two-way, real-time interactive communication, was limited to specific provider types and required that the originating site for a telemedicine consultation be an enrolled office location in the Medical Assistance program. No such limitations to the payment for telemedicine services were applied to the HealthChoices program.

Given the Governor's emergency disaster declaration and the Centers for Disease Control and Prevention's (CDC's) recommendations related to quarantine and isolation, both self-imposed and mandatory, OMAP is announcing a preference for use of telemedicine as a delivery method for medically necessary healthcare services beyond physician consultations and will pay for MA covered services as described below when rendered via telemedicine when the provider or practitioner determines it is medically necessary because the patient is quarantined, self-quarantined, or self-isolated due to exposure or possible risk of exposure to the COVID-19 virus. The Department recognizes a medical professional may not be available at the same location as the beneficiary. During this state of emergency, telephone only services may be utilized in situations where video technology is not available. Please note that Services rendered for the purposes of diagnosing or treating COVID-19 should be coded using the appropriate ICD-10 codes identified by the CDC. Providers should bill for the service as if they were provided face-to-face and in accordance with the MA fee schedule. Services rendered through telemedicine will be paid at the same rate as if they were rendered in-person at an enrolled location. Providers are not to use place of service (02). No additional payment will be made for the technology. Providers are to document in the beneficiary's record the service was rendered via telemedicine.

Telemedicine will continue to be available in the Physical Health HealthChoices program. In order to provide MA covered services using telemedicine to an individual enrolled in an MCO, a provider should contact the individual's MCO directly to negotiate payment for these services. Please refer to the Frequently Asked Questions document related to COVID-19 for the provider services phone numbers for each MCO. The Physical HealthChoices MCOs are able to pay for telemedicine services where the MCO's member is remotely located from the rendering provider. OMAP has instructed the MCOs to pay for telemedicine services wherever appropriate in a manner that meets or exceeds the fee-for-service coverage for telemedicine.

PROVIDER QUICK TIPS

Effective immediately, Pennsylvania's MA fee-for-service program will cover telemedicine services rendered under the following circumstances:

- The service is rendered by one of the following provider types:
  - 01: Inpatient Facility – **ONLY** for Specialty Code 183 (Hospital Based Medical Clinic)
  - 08: Clinic
  - 09: Certified Registered Nurse – **ONLY** for Specialty Code 093 (Nurse Practitioner (Primary Care))
  - 17: Therapist – **ONLY** for Specialty Codes 176 (Physical Therapy/Early Intervention), 177 (Occupational Therapy/Early Intervention), and 178 (Speech/Hearing Therapy/Early Intervention). Guidance issued by the Office of Child Development and Early Learning applies to these provider specialty types and may include requirements in addition to those included in this Quick Tip.
  - 31: Physician (Physician's Assistants may provide services under the usual direction of their supervising physician)
  - 33: Certified Nurse Midwife
- The service is rendered in conformance with the full description of the procedure code, in a clinically appropriate manner, and to the extent that it would have been rendered if the visit had occurred in-person.

This guidance will remain in effect while a valid disaster declaration by the Governor related to the COVID-19 virus remains in effect. OMAP may re-issue these guidelines as appropriate.

Additional information is also available on the CDC website and through CMS.

Information on MA Program coverage related to COVID-19, to include an FAQ document, can be found on the Department of Human Services website here.

The Pennsylvania Department of Health has a dedicated page for COVID-19 that provides regular updates. Click here for the most up to date information regarding COVID-19.

Thank you for your service to our Medical Assistance beneficiaries.
We value your participation.
Check the Department's website often at: www.dhs.pa.gov