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Behavioral Health Telehealth Services for Individuals with Intellectual Disabilities and/or Autism Project

Report

Commonwealth of Pennsylvania

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Mercer Government Human Services Consulting

A business of Marsh McLennan

Contents

1. Executive Summary ... 1

2. Overview of Process ... 4

- ID/A Telehealth Project Steering Committee ... 4
- Town Hall ... 5
- Survey ... 6
- Focus Groups ... 6

3. ID/A Telehealth Project Objectives ... 8

- Feedback by Theme ... 10
- Feedback by Focus Group ... 13
- Steering Committee Recommendations ... 15

Appendix A: ID/A Telehealth Project ... 17

- Summary of Initial Research ... 17
- Telehealth and Intellectual Disability and/or Autism ... 17

Appendix B: Town Hall Meeting Notes ... 24

Appendix C: Focus Groups: Notes ... 40

- ID/A Providers Focus Group One ... 40
- ID/A Providers Focus Group Two ... 44
- Family and Friends Focus Group ... 50
- Self-Advocates Focus Group ... 56

Section 1

Executive Summary

The option to access healthcare services via telehealth has increased dramatically in the past few years. Since the public health crisis, Coronavirus Disease 2019 (COVID-19), all 50 states and Washington DC allow behavioral health (BH) services to be delivered via telehealth. This includes providing these services to Medicaid members with an Intellectual Disability and/or Autism Spectrum Disorder (ID/A).

There are an estimated seven million individuals with ID/A in the United States. Approximately 20% are receiving services through Medicaid. This includes both children and adults with diagnoses ranging from mild to profound need. Many of these individuals also have a co-occurring BH diagnosis. It is estimated that at least 48% of adults with ID/A have a co-occurring anxiety diagnosis and nearly 78% of children with Autism Spectrum Disorder (ASD) have at least one BH condition, including anxiety[1]. As such, individuals with ID/A may experience more barriers to engaging in telehealth than other populations engaging in similar services. The Pennsylvania Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS) wanted to better understand the use of Behavioral Health Telehealth Services for individuals with ID/A in Pennsylvania. In particular, ODP and OMHSAS sought:

- To outline recommendations to optimize the use of BH telehealth with the ID/A population.
- To increase awareness of Pennsylvania ID/A providers' and stakeholders' telehealth use and interest.
- To strengthen ODP' and OMHSAS' relationships with ID/A stakeholders.
- To clarify and develop best practices for supporting co-occurring/complex diagnoses for the ID/A population.

To achieve these objectives, ODP engaged Mercer Government Human Services Consulting (Mercer), part of Mercer Health & Benefits LLC, to conduct research, facilitate discussions, and engage stakeholders through a survey, Town Hall, and focus groups.

An ID/A Telehealth Project Steering Committee (Steering Committee) was created to provide guidance on the project approach and ensure objectives were met. The Steering Committee of ODP and OMHSAS leadership was tasked to:

- Guide the approach to engage stakeholders including review and approval of the Town Hall and survey design.

[1] Maddox, B. B., & White, S. W. (2015). Comorbid Social Anxiety Disorder in Adults with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 45(12), 3949–3960. https://doi.org/10.1007/s10803-015-2531-5

- Identify questions that best target objectives for discussions with focus groups.
- Assess all stakeholder feedback and recommend ways to optimize the use of BH telehealth for individuals with ID/A.

Over approximately six months, Mercer met with 139 stakeholders; self-advocates, families and friends of individuals with ID/A, BH providers, and ID/A providers. Stakeholders provided feedback on their experience with telehealth for BH services including its benefits, challenges, and opportunities. Participation occurred through an online survey, virtual small group discussions at the Town Hall, and virtual focus group meetings.

The Steering Committee approved all communication with stakeholders and reviewed all feedback prior to determining recommendations. The recommendations to optimize the use of BH telehealth for individuals with ID/A proposed by the Steering Committee set the framework to guide informed choice in technology selection and to encourage best practices. In particular:

- ODP recommends provider organizations develop and provide training for specialists and other providers designed to support telehealth best practices.
- ODP recommends that telehealth is only used with intent, as the best modality service for the individual receiving the service. There should be ongoing periodic assessments to ensure the service modality selected remains the most appropriate modality. This recommendation will be implemented through policy and included as a best practice.
- It is recommended that policies are assessed to ensure they support the use of BH telehealth by individuals with ID/A. ODP intends to assess waiver service definitions to determine what is allowable and update the service standards to align, as appropriate.
- ODP recommends that there is a clear distinction between telehealth and remote monitoring. ODP intends to update policies with this distinction. A hybrid model for all services is preferred, with the individuals' preference prioritized.
- It is recommended that all providers serving individuals with ID/A receive training focused on best practices to engage individuals with ID/A using telehealth. ODP will expand the expectation for providers using telehealth to offer training to individuals with ID/A, and their families and friends, who will receive those services via telehealth. Training will be encouraged to align with National CLAS Standards.
- It is recommended that platforms are assessed for accessibility and detailed information shared with providers and telehealth users. ODP intends to build upon existing best practices for selecting platforms for telehealth services, in particular for accessibility.
- It is recommended that more information on telehealth is made easily available for individuals with ID/A. ODP will share more information on telehealth as an option to receive services for individuals with ID/A.

In addition, to addressing specific recommendations to optimize telehealth use, ODP also recommends that a future project is developed to determine telehealth best practices for individuals with complex needs.

The incredible engagement from stakeholders throughout the BH Telehealth Services for ID/A Project provided vital information for Steering Committee consideration. The candid feedback educated all involved on how individuals with ID/A experience telehealth in Pennsylvania and is already informing policy change at ODP and OMHSAS. While change takes time, the State is committed to ensuring individuals with ID/A are able to access the services they need in the modality they prefer. ODP and OMHSAS plan to build upon the relationships formed with stakeholders during this process, to continue to improve telehealth as a modality, and to create the foundation to adapt and evolve as technology changes.

Section 2

Overview of Process

The Pennsylvania Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS) wanted to better understand the use of Behavioral Health Telehealth Services for individuals with ID/A. In particular, ODP and OMHSAS sought:

- To outline recommendations to optimize the use of BH telehealth with the ID/A population.
- To increase awareness of Pennsylvania ID/A providers' and stakeholders' telehealth use and interest.
- To strengthen ODP' and OMHSAS' relationships with ID/A stakeholders.
- To clarify and develop best practices for supporting co-occurring/complex diagnoses for the ID/A population.

To achieve these objectives, ODP and OMHSAS engaged Mercer, a government consulting firm, to conduct research and engage stakeholders. The ID/A Telehealth Project was created to be guided by a Steering Committee, host a Town Hall meeting, conduct a survey, and facilitate focus groups.

ID/A Telehealth Project Steering Committee

The ID/A Telehealth Project was guided by a Steering Committee of ODP and OMHSAS leadership. ID/A Telehealth Project Steering Committee members:

Office of Developmental Programs (ODP)	Office of Mental Health and Substance Abuse Services (OMHSAS)
• Kristin Ahrens, Deputy Secretary • Amy Alford, Senior Clinical Consultant, Bureau of Supports for Autism and Special Populations • Dr. Greg Cherpes, Medical Director • Lauren House, Director, Bureau of Community Services • Marlinda Smith, Dual Diagnosis Initiative Project Lead • Nina Wall, Director, Bureau of Supports for Autism and Special Populations	• Dr. Dale Adair, Medical Director/Chief Psychiatric Officer • Amy Kabiru, Licensed Social Worker, Children's Bureau • Jennifer Mehnert Baker, Director, Bureau of Policy and Planning • Kayla Sheffer, Human Services Supervisor

The ID/A Steering Committee provided guidance on project design, the Town Hall, survey development, focus groups' membership, and focus groups' questions. The Steering Committee also informed all recommendations outlined in this report.

Town Hall

The Town Hall was held via Zoom and designed to engage all stakeholders. The Town Hall had attendees representing:

- Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR)
- The Provider Alliance (TPA)
- Rehabilitation and Community Providers Association (RCPA)
- The Arc
- Pennsylvania Family Network
- Self Advocates United as 1 (SAU1)
- Speaking for Ourselves
- Vision for Equality
- Office of Long-Term Living
- Mental Health Planning Council (MHPC)
- The Autism Services, Education, Resources, and Training Collaborative (ASERT)
- Health Care Quality Units (HCQU)
- PennABA
- BH-managed care organization (MCO) and MCO representatives
- County representatives/administrative entities
- Self-advocates, families and friends

The Town Hall provided an overview of current work by ODP and OMHSAS, an introduction to the ID/A Telehealth Project, and time to gather initial feedback from small groups. Small groups were organized by role/perspective and included BH Providers, ID/A Providers, Self-Advocates, and Friends and Family.

Dr. Greg Cherpes, ODP Medical Director, shared information on collaborative capacity building initiatives: Annual Dual Diagnosis Conference, Dual Diagnosis Curriculum, and Functional Behavior Assessment Training. In addition an overview of the four newer initiatives was provided:

- START: Systematic Therapeutic Assessment Resources and Treatment
- TRAIN: Trauma Recovery for Autistic, Intellectually Disabled, and Neurodivergent Individuals
- Project Reassure: Resilience and Stress Management for Neurodiverse Communities
- BH Telehealth Services for Individuals With ID/A Project

Jenna Mehnert Baker, OMHSAS Director of the Bureau of Policy, Planning, and Program Development spoke to previous telehealth work; a memorandum on telehealth guidelines related to COVID-19, temporary suspension of specific regulations, 2020 BH Telehealth Steering Committee Project, OMHSAS bulletin 22-02, legislative action, and ongoing monitoring for telehealth developments.

The Town Hall attendees were then provided an overview of the ID/A Telehealth Project including objectives, stakeholder engagement opportunities, surveys, and focus groups.

Following information on what work was underway and planned for the future, attendees divided into small groups to provide feedback on their current telehealth use and experience. Detailed notes on this feedback can be found in Appendix B.

Survey

An online survey was designed to gather feedback from a wide range of stakeholders. The survey was also tailored to each stakeholder group: Family and Friends, Self-Advocates, BH Providers, and ID/A Providers. The survey questions were tailored to each audience while also remaining aligned with focus group themes:

- Understanding the Stakeholder Experience: Current care and potential barriers to delivering/receiving telehealth services for individuals with ID/A.
- BH services for telehealth in Pennsylvania for individuals with ID/A.
- Discussion on technology use, current regulations, and data.
- Discussion on best practices and what stakeholders would like to learn.

The surveys were sent following the Town Hall and each focus group meeting. There were 35 responses to the survey. More details on feedback provided in the survey may be found in Appendix D.

Focus Groups

Focus groups were structured to engage stakeholders in compatible groups. As such, four groups were created: Self-Advocates, Family and Friends, BH Providers, and ID/A Providers. Initially the focus groups were designed to be conducted in two sessions for each group. However, due to feedback from BH Providers, Self-Advocates, and Family and Friends, the approach was restructured. The BH Providers provided strong feedback at the Town Hall, through the survey, and in a former Telehealth Project. As such, there were no focus groups with the BH Providers. The Self-Advocate and Family and Friends groups invited the ID/A project team to attend already scheduled meetings, preferring condensed focus group discussions. The updated approach succeeded in capturing feedback from a variety of stakeholders in the setting that worked best for them.

Two two-hour ID/A Provider sessions were held, each targeting a different series of questions aligning with the themes noted earlier. Eleven providers attended the two sessions. Detailed notes from those sessions are in Appendix C.

There were three one-hour Self-Advocate sessions. These meetings were held during already scheduled meetings times with Self Advocates United as 1 (SAU1), Judith Creed Horizons for Achieving Independence (JCHAI) Self-Advocates, and Spectrum Friends. Attendees included coordinators, power coaches, direct support professionals, and self-advocates. Questions were designed around four themes: Telehealth Basics, Independence, Accommodations, and Communication. Detailed notes from these sessions are in Appendix C.

The final focus group was held with families and friends of individuals with ID/A. This included two one-hour focus group meetings with the Pennsylvania Family Network and the JCHAI Family/Friends group. Detailed notes from these sessions are in Appendix C.

Section 3
ID/A Telehealth Project Objectives

The ID/A Telehealth Project was designed to address four objectives:

- To outline recommendations to optimize the use of BH telehealth with the ID/A population.
- To increase awareness of Pennsylvania ID/A providers' and stakeholders' telehealth use and interest.
- To strengthen ODP' and OMHSAS' relationships with ID/A stakeholders.
- To clarify and develop best practices for supporting co-occurring/complex diagnosis for ID/A population.

A summary of the approach to achieve each objective and the outcomes of that work is provided below.

Objective 1: To increase awareness of Pennsylvania ID/A providers' and stakeholders' telehealth use and interest.

Through the Town Hall, survey, and focus groups, feedback was gathered on telehealth use and interest from approximately 139 stakeholders representing a wide variety of organizations:

- Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR)
- The Provider Alliance (TPA)
- Rehabilitation and Community Providers Association (RCPA)
- The Arc
- Pennsylvania Family Network
- Self Advocates United as 1 (SAU1)
- Speaking for Ourselves
- Vision for Equality
- Office of Long-Term Living
- Mental Health Planning Council (MHPC)
- The Autism Services, Education, Resources, and Training Collaborative (ASERT)
- Health Care Quality Units (HCQU)
- PennABA
- BH-MCO and MCO representatives
- County representatives/administrative entities
- Self-advocates, Family and friends

The responses from stakeholders provided a variety of perspectives. In particular, information shared at the Town Hall informed changes to the focus group questions and meeting approaches. It also provided insight on how use and interest varied between provider types. Through the process, ODP and OMHSAS became more aware of how Pennsylvania ID/A providers and stakeholders used telehealth and how interest and reasons for using telehealth varied among stakeholders.

Objective 2: To strengthen ODP'/OMHSAS' relationships with ID/A stakeholders.

The ID/A Telehealth Project demonstrated the commitment of ODP and OMHSAS to engage individuals with lived experience and community members. Relationships and awareness on both sides increased though a Town Hall, survey, and focus groups. In particular, information on current ODP and OMHSAS initiatives that may impact individuals with ID/A was shared at each focus group meeting. Additional information and links to reports was also provided via email following all interactions with stakeholders. Scheduling focus groups also increased ODP and OMHSAS awareness of the strong advocacy network, standing stakeholder meetings, and opportunities for future engagement with groups demonstrating strong work in the ID/A space. Some of the groups noted during the project:

- Adult Community Autism Program (ACAP)
- Client Assistant Program (CAP)
- JCHAI Support Group for Parents
- SPECTRUM SUCCESS 911
- Posibilidades Infinitas
- HUNE
- Unending Promises
- Vision for Equality
- Autism Society Greater Harrisburg Area Affiliate
- Autism York
- CPARC Parent Group Meet Up
- Facing Forward
- Autism Connection of Pennsylvania
- Autism Pittsburgh (Pittsburgh area)
- Parents in Toto (Butler area)
- Autism Urban Connections Inc. (Pittsburgh area; minority focused)
- Autism Society Northwestern Pennsylvania (Erie area)
- HEROES (Warren area)

Objective 3: To clarify and develop best practices for supporting co-occurring/complex diagnosis for ID/A population.

There was not enough information received from stakeholders regarding co-occurring/complex diagnoses for ID/A population to clarify and develop best practices. However, there were lessons learned that may help assist exploring this area further in the future. Considerations if this objective is explored further in future:

- Recommend "complex" is clearly defined.
- May require individuals share more personal information as it requires identifying as "complex". As such, may be better as a standalone objective with a focus group focused on co-occurring/complex diagnoses.
- Recommend that parameters are identified to guide development of best practices.

Information gathered from stakeholders particular to this objective maintained telehealth could be a useful tool to for this population. In particular, noting that:

- Assistive devices could enhance community inclusion, such as timed pillboxes or virtual monitoring to assist individuals with activities of daily living.
- For individuals with more complex needs, telehealth can be particularly useful in times of crisis so the provider can get a full picture.
- There should be open communication and a plan for how telehealth is going to be utilized for the particular person.
- There should be a meet and greet with family and friends, care team, etc. to share information about telehealth, how it can be used, and why it can be helpful. This is especially helpful for individuals with complex needs.

Objective 4: To outline recommendations to optimize the use of BH telehealth with the ID/A population.

Throughout the ID/A Telehealth Project, the Steering Committee provided guidance on focus group questions, follow up approaches, and research. At the final Steering Committee meeting, the group reviewed feedback gathered from the survey, Town Hall, and all focus group meetings. To assist in the assessment, the feedback was summarized by theme (Telehealth Use, Benefits of Telehealth, Challenges of Telehealth, Training, Privacy, and Future of Telehealth) and by group (Self-Advocates, Family and Friends, BH Providers, and ID/A Providers). An overview of the information shared is below.

Feedback by Theme

Telehealth Use

- Almost unanimous use of telehealth was reported by Self-Advocates, Family and Friends, ID/A Providers, and BH Providers. However, quite a few Self-Advocates had limited telehealth experience beyond social groups, and community-based involvement.
- Self-Advocates and Family and Friends reported that they use telehealth for a variety of services including BH treatment, therapy, counseling, and primary care appointments.
- ID/A Providers reported using a variety of telehealth platforms for a wide array of services including parent/caregiver training, scheduled/routine visits, unscheduled or spontaneous appointments as well as provider assessments in which supervisors can attend appointments virtually to assess the provider.
- BH Providers also report using telehealth in a variety of ways, including supervision with out-of-state providers and in circumstances when the individual receiving services is sick or in isolation due to COVID-19 and cannot attend an in-person appointment.
- All stakeholders plan to continue to use telehealth post-public health emergency (PHE); however, a majority of Self-Advocates want to use it less than during the PHE.

Benefits of Telehealth

- Telehealth services garnered stronger support from Family and Friends, ID/A Providers, and BH Providers than Self-Advocates. The majority of Self-Advocates prefer in person with a few strong supporters of telehealth.
- It is flexible, easier time rescheduling and getting appointments, especially in rural areas. Provides access to more services for Deaf/Blind groups and Gender Identity Therapy, and ability to attend appointments during bad weather. Assists access for people with physical disabilities or mobility challenges.
- Convenient and reduces both time spent in transit/commuting and money spent on gas mileage.
- Reduced anxiety around telehealth appointments compared to in-person appointments. Minimizes exposures to illness.
- Supports provider well-being, retention, and collaboration opportunities.
- Allows providers to “meet the person where they are at” meaning that individuals can participate in telehealth from the comfort of their preferred space and environment.

Challenges of Telehealth

- Inhibits communication, expression of feelings, building trust/rapport, and reading body language/cues as compared to in-person services.
- Difficult for some younger children.
- Multiple groups reported technology challenges and challenges associated with using multiple platforms.
- Telehealth risks enabling less socialization and increased isolation. NOTE: In the Town Hall a Self-Advocate explained that the discussion of "forced socialization" from the provider point of view disregards individual choice/autonomy.
- Challenging to engage participants who may have a hard time sitting still for extended periods or looking at themselves on camera.
- It is easier to ensure privacy during in-person services.

Training

- Family and Friends, and Self-Advocates reported minimal-to-no training to use telehealth tools after the onset of the PHE. Learning telehealth almost unanimously occurred out of necessity during the PHE.
- ID/A Providers and Family and Friends encouraged the idea of further training around telehealth use. Family and Friends spoke to the idea that providers could use more training, as some are better with telehealth than others.

- Some Self-Advocates reported that they would like further support with telehealth in-the-moment, such as assistance to login or trouble shoot connectivity issues. This support noted as more important that stand-alone training to use telehealth.
- All groups reported that telehealth has gotten easier to use as time has gone on, and trial and error is a big component of that.
- ID/A Providers noted most of their training regarding telehealth occurred at the onset of the PHE and was supported by IT departments, but they do not have ongoing training.

Privacy

- Family and Friends appreciated acknowledgement of privacy by providers in a variety of ways including: asking the individual receiving services if they were okay with the friend/family/support presence in the room, letting them know the provider is alone, and asking for permission to invite the family/friend in at the end of an appointment.
- Participants felt more secure and assured when privacy was acknowledged.
- Challenges of privacy at home, making it difficult to have private telehealth appointments.
- Self-Advocates described needing support in accessing telehealth, but with support staff it means there is less privacy. Some mentioned that it is easier to share more personal information through a screen, while others were nervous about sharing details about issues such as family conflict through telehealth because of lack of privacy.
- It was noted that if an individual with ID/A resides in a facility the computers may be at a nurses station or in a shared space.
- Providers noted cost concerns around Health Insurance Portability and Accountability Act (HIPAA) compliant platforms and not all were aware of the requirement to use HIPAA compliant platforms.

Future of Telehealth

- Technical support, including in-the-moment assistance, and feedback opportunities.
- Telehealth integration into electronic health records (EHRs).
- Widespread support for making telehealth simpler. Examples include consistency of platform and fewer steps to login to the appointment.
- More training for providers on how to connect/be more engaging through telehealth.
- Uniformity in billing codes, different requirements for in-person versus telehealth services code/billing processes.
- Increased support/use of closed captioning and funding for equipment and broadband.
- Support expansion of smart home and total technology.

- Need for enhanced training.
- Additional funding for equipment and access.
- View more than the face.
- Expansion of services, increased rates, incentives for telehealth, and augmentative reality.
- Address the lack of sensory experience.

Feedback by Focus Group

Self-Advocates

- Expressed strong preference for in-person appointments.
- Emphasized that telehealth is less anxiety inducing compared to in-person services. The comfort of one's own space was mentioned many times as a way to feel more at-ease during appointments.
- Relayed a desire for a place for feedback for telehealth appointments, specifically for technology use.
- Some distrust/fear around using telehealth and trusting the technology.
- Expressed that telehealth appointments can better support varying work schedules and other scheduled activities they participate in. Many enjoyed this flexibility while also acknowledging that telehealth brings its own challenges.
- Described how telehealth, in some cases, allows them to participate in activities they may not normally be able to take advantage of in person, such as social groups far from their homes.
- Some participants noted a desire to return to in-person services but implied resistance from providers to allow that option again.

Family and Friends

- Telehealth does not allow for psychosocial interactions and may encourage isolation for some individuals.
- There have been successes for individuals with extremely complex needs, although specialists may function in siloes and need to have more communication with each other.
- Individuals receiving services via telehealth should have a required in-person touch base, for example every six months.

- Requires more attention from families and friends to support telehealth visits versus in person. It is helpful to have someone with the individual during a telehealth visit to assist the individual and to also ensure the clinician is aware of issues that might not be easily visible.
- Telehealth allows for more family flexibility, such as the individual receiving services participating in a telehealth appointment at home, while the parent is at work/out of the house.
- Some providers are better than others at engaging individuals over telehealth. Some providers seem to have welcomed the challenge and found creative ways to take advantage of telehealth, such as using visuals for behavior goal tracking that allows providers to collect data. Other providers have struggled to engage with the individual receiving services over telehealth.

Mental Health Providers

- Compliance is difficult; there can be contradictory information from MCOs.
- Lots of potential for increased collaborative care between providers and specialists.
- Telehealth may not provide individualized care/rapport of someone checking in. BH providers reported that it risks being a quick transaction “to check a box”.
- Specific to family/therapist telehealth is a mixed bag as it can assist immediate intervention when a crisis occurs but may have problems with technology, attention, quality, and privacy.
- Can increase access to specialists such as for eating disorders that may not be easy to access in the community.
- Can allow for greater diversity in treatment providers, such as access for individuals who speak different languages or are BIPOC or LGBTQIA+.

ID/A Providers

- Assists with staffing problems, allows providers to meet staffing demands of their patients by filling open positions with virtual staff.
- Allows providers to meet the needs of their patients:
  - For intimate/emotional discussions, i.e., sexual identity/support, it is easier for patients to speak because there is less embarrassment than having someone physically in the room and allows for a deeper conversation.
  - For rural patients there is increased access to care, i.e., psychiatry assistance available in areas where there are not providers.
- Provides new opportunities to observe the individual in important settings such as school.

- Noted costs to license platforms, Augmentative and Alternative Communication (AAC) devices, technology security, and supporting technology for members using iPads.
- Cost savings have occurred through downsizing physical office space, decreasing gas mileage and wear and tear on vehicles.
- The ID/A telehealth platform is not as robust as the BH and medical telehealth platform. Those platforms are integrated. ID/A Providers would like to see telehealth integrated into the electronic medical record/electronic health record (EMR/EHR).

General Comments

In addition to reviewing the information above, the group also discussed general comments and observations made throughout the process. In particular:

- Comment on use of the terminology ID/A: A participant inquired about the grouping of Intellectual Disability with Autism. They expressed their desire that the differences in need between these two populations is documented in notes and in future recommendations. They expressed gratitude for the services ODP provides, but expressed concern over the two groups being "lumped together". This was supported by other participants. Support was given to the suggestion of individualization being important when discussing the benefits and challenges of services via telehealth.
- Language used to describe telehealth: In meetings with Self-Advocates the terminology "telehealth" was often misinterpreted to apply to medical/physical health appointments only. As such, facilitation used "Zoom" to better engage the groups on how they use telehealth for BH appointments and other social/community engagement. Other language in practice is "tele-behavioral-health".
- Standing Family and Friends and Self-Advocates groups were engaged. As such, feedback may more strongly represent thoughts by participants quite familiar with using technology to connect.

Steering Committee Recommendations

The Steering Committee recommendation is to optimize the use of BH telehealth with the ID/A population.

Following the review of stakeholder feedback the Steering Committee discussed how best to optimize the use of BH telehealth for individuals with ID/A. The recommendations balance the States inability to dictate specific technologies and State resource limitations with a strong desire to improve telehealth access and quality for individuals with ID/A. As such, the recommendations set the framework to guide informed choice in technology selection and to encourage best practices. In addition, recommendations set the stage for ODP and OMHSAS to assess current policy to ensure it aligns with recommendations. In particular:

- ODP recommends provider organizations develop and provide training for specialists and other providers designed to support telehealth best practices.

- ODP recommends that telehealth is only used with intent, as the best modality service for the individual receiving the service. There should be ongoing periodic assessments to ensure the service modality selected remains the most appropriate modality. This recommendation will be implemented through policy and included as a best practice.
- It is recommended that policies are assessed to ensure they support the use of BH telehealth by individuals with ID/A. ODP intends to assess waiver service definitions to determine what is allowable and update the service standards to align, as appropriate.
- ODP recommends that there is a clear distinction between telehealth and remote monitoring. ODP intends to update policies with this distinction. A hybrid model for all services is preferred, with the individuals' preference prioritized.
- It is recommended that all providers serving individuals with ID/A receive training focused on best practices to engage individuals with ID/A using telehealth. ODP will expand the expectation for providers using telehealth to offer training to individuals with ID/A, and their families and friends, who will receive those services via telehealth. Training will be encouraged to align with National CLAS Standards.
- It is recommended that platforms are assessed for accessibility and detailed information shared with providers and telehealth users. ODP intends to build upon existing best practices for selecting platforms for telehealth services, in particular for accessibility.
- It is recommended that more information on telehealth is made easily available for individuals with ID/A. ODP will share more information on telehealth as an option to receive services for individuals with ID/A .

In addition, to addressing specific recommendations to optimize telehealth use, ODP also recommends that a future project is developed to determine telehealth best practices for complex needs.

Appendix A

ID/A Telehealth Project

Summary of Initial Research

Telehealth and Intellectual Disability and/or Autism

Telehealth services have been increasing in popularity over the past few years. Prior to the Coronavirus Disease 2019 (COVID-19) public health crisis, 42 states permitted telehealth for BH services to be provided. Since the public health crisis, all states and Washington DC permit some BH service and medical services to be provided using telehealth. Telehealth services includes both audio/video and audio-only tools. Telehealth has been shown to be beneficial not only for the agencies providing the services, but also the populations receiving services that may have faced barriers when services were provided in person. This includes the population of Medicaid users diagnosed with an Intellectual Disability (ID) or the Autism Spectrum Disorder (ASD),[2] also known as the ID/A (Intellectual Disability/Autism) population.

Current Use of Telehealth for the ID/A Population

There are an estimated seven million individuals with ID/A. Approximately 20% are receiving services through Medicaid[3]. Diagnoses can range in this population from mild to profound needs. The range of needs necessitates a highly skilled and diverse workforce as well as a variety of services. As a result, ID/A needs may present more barriers to engaging in telehealth than other populations engaging in similar services due to the complexities that can be seen outside of telehealth services as well.

Common Telehealth Services

- Mental health services conducive to serving the ID/A population include:
  - Psychiatric Care and Telemedicine
  - Cognitive Behavior Therapy
  - Dialectical Behavior Therapy
  - Individual and Family-Based Therapies
  - Social Groups/Social Therapy

[2] Chu, R. C., Peters, C., de Lew, N., & Sommers, B. D. (2021). State Medicaid Telehealth Policies Before and During the COVID-19 Public Health Emergency. ASPE Office of Health Policy. https://aspe.hhs.gov/sites/default/files/2021-07/medicaid-telehealth-brief.pdf#:~:text=Some%20state%20Medicaid%20programs%20have%20been%20innovators%20and,and%2036%20states%20did%20so%20for%20primary%20care

[3] Siegel, A., Zuo, Y., Moghaddamcharkari, N., McIntyre, R. S., & Rosenblat, J. D. (2021). Barriers, benefits and interventions for improving the delivery of telemental health services during the coronavirus disease 2019 pandemic: a systematic review. Current Opinion in Psychiatry, *34*(4), 434–443. https://doi.org/10.1097/yco.0000000000000714

- Assessments that may include:
  - BH Initial and Ongoing Assessments
  - Screening Assessments and Tools
  - Diagnostic Assessments including Psychiatric and Neuro-Psychological Assessments
- Coordination of Care
- Applied Behavior Analysis (ABA)
  - ABA services are a good example of a service that may be best served using a hybrid model to ensure fidelity while still allowing for some of the benefits of telehealth
- Speech and Language Therapy
- Parent Training and Support
- Sibling Support Groups

Benefits of Telehealth for the ID/A Population

- An Agency for Healthcare Research and Quality report found that telehealth use has demonstrated positive outcomes for remote monitoring and counseling consumers with chronic conditions. The report looks at the efficacy of evidence-based practices and their outcomes in multiple areas of counseling and psychotherapy.[4]
- Telehealth can be used as an alternative modality for the community if the child or adult has health concerns, issues with childcare, distance to patient (either from the clinic or available direct care workers), or there are staffing factors (e.g., insufficient staff available locally).
- Well-established diagnostic measures for those individuals with or looking for an ASD diagnosis (i.e., Autism Diagnostic Observation Schedule and Autism Diagnostic Interview-Revised), as well as other measures of ASD symptomology, can be used via telehealth successfully as accurate alternatives for identifying children with ASD rather than solely relying on in-person assessments[5]. This includes further assessment models such as a Functional Behavior Assessment, Functional Analysis, or a preference assessment that are frequently used to guide behavior interventions.

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[4] Oss, M. E. (2021, November 3). Yes, Telehealth Does Work For Consumers With I/DD. OPEN MINDS. https://openminds.com/market-intelligence/executive-briefings/yes-telehealth-does-work-for-consumers-with-i-dd/

[5] Ellison, K. S. (2021, June 10). Telehealth and Autism Prior to and in the Age of COVID-19: A Systematic and Critical Review of the Last Decade. SpringerLink. https://link.springer.com/article/10.1007/s10567-021-00358-0?error=cookies_not_supported&code=ed1e6aeb-35ca-43cd-8809-7f437cfdc544#citeas

- Studies have shown ongoing skill development in language, adaptive living, coping, and tolerance skills, and social domains can be effective when telehealth is used as a modality[6]. This includes both naturalistic teaching and discrete trial training with varying levels of caregiver involvement.
- Many children and adults with ID/A find benefit in telehealth services to help reduce anxiety around face-to-face interactions, travel, driving, etc. It is currently estimated that at least 48% of adults with ID/A have a co-occurring anxiety diagnosis; however, many studies show this is a gross underrepresentation.[7] It is estimated that nearly 78% of children with ASD have at least one BH condition, including anxiety.[8]
- There are cost saving benefits of providing telehealth including:
  - Lowered travel expenses.
  - The ability/time to see more clients during the day.
  - Lowered likelihood of cancelations due to common concerns such as lack of transportation, running late, work schedules, etc.
  - All of these are especially true for higher billing clinicians who can perform supervision, parent training, or direct work through telehealth while support staff may be in person.
    - For example: Average use of telehealth ABA hours is 5.4–20.9 hours per week.[9] The majority of the hours are implemented by the behavioral therapists, with 1.0–5.0 hours per week being check-ins from the supervisor (Board Certified Behavior Analyst). Telehealth allows for supervisors to check-in with more families and staff throughout the week.

Telehealth Barriers for the ID/A Population

- It is recommended that telehealth direct therapy rely heavily on caregiver support and facilitation to promote generalization and increase in outcomes.[10] This depends on a variety of factors such as:
  - Whether the patient or their caregivers has access to the internet and a device to participate in telehealth services.

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[6] Nohelty, K. (2021, July 12). Effectiveness of Telehealth Direct Therapy for Individuals with Autism Spectrum Disorder. SpringerLink. https://link.springer.com/article/10.1007/s40617-021-00603-6?error=cookies_not_supported&code=c584b04f-ddb7-43a3-9ed8-7593beb3f949

[7] Maddox, B. B., & White, S. W. (2015). Comorbid Social Anxiety Disorder in Adults with Autism Spectrum Disorder. Journal of Autism and Developmental Disorders, 45(12), 3949–3960. https://doi.org/10.1007/s10803-015-2531-5

[8] OPEN MINDS. (2021, February 6). Nearly 78% Of Children With Autism Have At Least One Mental Health Condition. https://openminds.com/market-intelligence/news/nearly-78-of-children-with-autism-have-at-least-one-mental-health-condition/

[9] Nohelty, K. (2021, July 12). Effectiveness of Telehealth Direct Therapy for Individuals with Autism Spectrum Disorder. SpringerLink. https://link.springer.com/article/10.1007/s40617-021-00603-6?error=cookies_not_supported&code=c584b04f-ddb7-43a3-9ed8-7593beb3f949

[10] Nohelty, K. (2021, July 12). Effectiveness of Telehealth Direct Therapy for Individuals with Autism Spectrum Disorder. SpringerLink. https://link.springer.com/article/10.1007/s40617-021-00603-6?error=cookies_not_supported&code=c584b04f-ddb7-43a3-9ed8-7593beb3f949

- Whether the patient is able to safely receive telehealth direct therapy without the perceived risk of engagement in severe challenging behaviors that would endanger the patient and others around them.
- Whether a caregiver is available to assist in the facilitation of therapy sessions to the extent recommended by the primary supervisor.

- There is a lack of training for both clinicians and support staff on how to provide BH services to those with ID/A[11], with or without telehealth being a service delivery. This includes a limited standard of care when working with the population.
- There may be atypical representation of symptoms making it more difficult to treat.
  - For individuals in the ID/A population, especially those with co-occurring BH conditions, it can often be difficult to determine what symptomology stems from the disability, BH condition, or combination of both.
  - As such, more observation time and face-to-face interactions may be needed to appropriately determine the function of the behavior/symptom in order to determine the correct intervention strategy.
- There is a higher prevalence of children with ID/A that have been exposed to trauma.[12] While research shows benefits of trauma therapy by telehealth, there has not been research done on this specific population receiving trauma focused services via telehealth (Trauma Focused Cognitive Behavior Therapy, Eye Movement Desensitization and Reprocessing). Please note that this does not include basic trauma informed care.
- There are increased costs when providing telehealth services. Components of providing telehealth services that incur additional costs include:
  - Providing technology and equipment to staff that may otherwise not require the equipment (i.e., direct support staff).
  - Ensuring individuals receiving services have access to technology and a secured internet connection.
  - Ensuring telehealth software is Health Insurance Portability and Accountability Act (HIPAA) compliant, (initial investment and ongoing costs).

[11] Moody, PhD, E. (2022). IDD and Mental Health | Mental Health Technology Transfer Center (MHTTC) Network. https://mhttcnetwork.org/centers/mountain-plains-mhttc/product/idd-and-mental-health

[12] Moody, PhD, E. (2022). IDD and Mental Health version 2 | Mental Health Technology Transfer Center (MHTTC) Network. https://mhttcnetwork.org/centers/mountain-plains-mhttc/product/idd-and-mental-health

HIPAA

Health Insurance Portability and Accountability Act (HIPAA) compliance continues to be a concern for most providers as well as Centers for Medicare & Medicaid Services. In 2020, the Health and Human Services Office for Civil Rights issued a Notification of Enforcement Discretion for Telehealth remote communications during COVID-19, which relaxed HIPAA requirements for telehealth services. However, as the public health emergency (PHE) comes to an end, many states, including Pennsylvania, have moved towards recommending HIPAA compliant telehealth platforms.

Examples of telehealth platforms that claim to be HIPAA compliant include Doxy.me, Skype for Business, Updox, TheraNest, and Zoom for Healthcare[13].

Health Equity

Telehealth services can ensure equal access to quality care for everyone[14]. This includes:

- Being able to provide services to otherwise underserved Americans including — low income households, those living in rural areas, people of color, immigrants, those with limited knowledge of the English language, among others.
  - Many agencies, especially throughout the COVID-19 PHE, have continued to struggle with staffing shortages. Telehealth allows for limited staff to address the needs of their community independent of geographical location or any language barriers.
  - Providers must remain vigilant of continued barriers including lack of access to internet, computer access, and a safe and secure place to engage in telehealth services.
- There are access considerations to remember, especially when working with the ID/A population.
  - Materials: Consider formats, materials, and language used.
    - Often need more visuals and interactive technologies.
  - Time: Extra time could be beneficial if an individual struggles with transitions.
  - Measuring patient satisfaction using post session check-in with individuals and care givers.

[13] OPD/OMHSAS does not endorse or recommend any platform

[12] Health equity in telehealth | Telehealth.HHS.gov. (2022). Telehealth.Gov. https://telehealth.hhs.gov/providers/health-equity-in-telehealth/

States Using Specific Telehealth Models

- Some states are exploring pilot programs that focus on specific telehealth services for the ID/A community including:
  - New Jersey, Ohio, Maryland, Tennessee, and Missouri have contracted and/or are engaged in pilot programs with StationMD. StationMD provides 100% telehealth services specifically to the ID/A population[15] such as:
    - Primary care/physical health services.
    - Urgent care for both physical health and BH needs.
    - BH including both psychological and psychiatric services.
      - Medication management and optimization.
      - Development of crisis plans for high risk individuals.
      - Coordination of care.
      - General and group counseling.
      - Cognitive and adaptive functioning testing, including the Vineland.
      - Evaluation for Intermediate Care Facility admission.
  - Ohio is engaging in a pilot program to determine the benefits of tele-psychiatry for those dually-diagnosed with ID/A and a BH disorder. The pilot includes an in-person initial assessment and follow-up telehealth psychiatry appointments.[16]
  - Texas is currently engaged in a STAR+PLUS Pilot[17]. A typical STAR program includes service coordination, acute care, long-term services and supports, housing supports, and employment assistance for adults dually-diagnosed with ID/A and BH. The STAR+PLUS program model mandates services should include telemedicine, tele-monitoring, and remote monitoring to promote community integration.

[15] StationMD. (2022, August 4). Behavioral Health Services — StationMD. https://stationmd.com/behavioral-health/
[16] Ohio Department of Developmental Disabilities. (2022). Ohio's Telepsychiatry Project for Intellectual Disability. DODD. https://dodd.ohio.gov/about-us/MIID/Telepsychiatry
[17] OPEN MINDS. (2022, April 8). Texas Medicaid Rebids STAR+PLUS Managed Care Plans For Members With Disabilities, Includes I/DD Pilot. https://openminds.com/market-intelligence/news/texas-medicaid-rebids-starplus-managed-care-plans-for-members-with-disabilities-includes-i-dd-pilot/

- The Council on Quality Leadership completed a national study to explore telehealth service delivery with individuals receiving services through a home- and community-based services (HCBS) waiver noting the variety of services used by the ID/A population.[18] Full study can be found here.
  - As of 2022, only 19 states have updated their HCBS waivers for the permanent use of telehealth as a tool to provide services to individuals with ID/A. All other states have a temporary waiver that is dependent on the continued PHE.
  - Of the 185 services that are approved for telehealth, whether permanent or temporarily, employment, day, and prevocational services; in-home and residential supports; and clinical and therapeutic services were the most prevalent.
  - There are some states who only allow individuals to use telehealth if they are able to do so independently. The study noted that this greatly limits the amount of individuals in the ID/A population who could otherwise benefit from telehealth services.

[18] The Council on Quality and Leadership. (2022, June 14). Telehealth in HCBS for People with Intellectual and Developmental Disabilities. https://www.c-q-l.org/resources/articles/telehealth-in-hcbs-for-people-with-intellectual-and-developmental-disabilities/

Appendix B

Town Hall Meeting Notes

Subject: Pennsylvania BH Telehealth Services for Individuals with ID/A

Meeting Date: November 7, 2022

Location: Zoom

- Welcome and introductions (slides 3–5):
  - Shannon Kojasoy with Mercer opened up the meeting by thanking everyone for coming.
    - The ID/A Steering Committee members were listed and introduced.
    - Dr. Gregory Cherpes welcomed attendees:
      - Pennsylvania Advocacy and Resources for Autism and Intellectual Disability (PAR), The Provider Alliance (TPA), Rehabilitation and Community Providers Association (RCPA), The Arc, Pennsylvania Family Network, Self Advocates United as 1 (SAU1), Speaking for Ourselves, Vision for Equality, Office of Long-Term Living, Mental Health Planning Council (MHPC), The Autism Services, Education, Resources, and Training Collaborative (ASERT), Health Care Quality Units (HCQU), PennABA, BH-MCO and MCO representatives, county representatives/administrative entities, self-advocates, and Family and friends.
- Office of Developmental Programs (ODP) and the Office of Mental Health and Substance Abuse Services (OMHSAS) (slides 6–18):
  - Dr. Gregory Cherpes provided an overview of initiatives underway in OMHSAS and ODP.
    - Consistent access to quality health care and supports is a major goal for the projects mentioned.
    - Telehealth is a way to increase health care equity.
    - In 2016, ODP and OMHSAS implemented the Collaborative Capacity Building Initiatives, a series of projects focusing on complex needs for individuals with IDD/Autism and BH needs.
    - Goals for these initiatives are:
      - Increase capacity to serve vulnerable populations.
      - Increase capacity for integrated settings.

    - Promote trauma informed approaches.
    - Promote practice for recovery.
    - Offer caregiver training.
    - Offer provider training and involvement.
- ODP and OMHSAS working together with four new initiatives:
  - START: Systematic Therapeutic Assessment Resources and Treatment:
    - Promotes excellence for those with Intellectual and Developmental Disabilities (I/DD) and START model.
    - START program since 1988, provides cross system crisis intervention.
- TRAIN: Trauma Recovery Needs for Autistic Intellectually Disabilities and Neuro-Divergent Individuals:
  - Intended for licensed clinicians who offer psychotherapy services.
  - Designed to support licensed clinicians to use evidence-based practice to meet trauma needs.
- Project Reassure: Resilience and stress management for neuro-diverse communities:
  - Trauma education and resilience building resources aimed at neuro-diverse communities.
  - Five stakeholder groups: Self-Advocates, Family Members/Natural Supports, DSPs, LMSPs, LMSPs in the Extension for Community Healthcare Outcomes (ECHO) outreach program.
  - Based on community resilience model.
  - Four core courses: Trauma and Trauma Expressions, Resilience and Resilient Zone, Core Resilience Buildings Skills, Resilience Skills Application.
  - Community collaborators: Self Advocates United as 1 (SAU1), the Acres Project, DSP, LMSP, and family inputs.
  - ECHO an all teach, all learn, spoke and hub model, with seven-week intervention covering a variety of flash talk topics.
- Jenna Mehnert Baker provided an overview of OMHSAS' previous telehealth work.
  - Progress towards current telehealth guidelines and flexibilities:
    - The work of both the first and second committee have helped to inform current OMHSAS telehealth policy.

    - OMHSAS current work:
      - OMHSAS bulletin.
      - OMHSAS sought legislative action to repeal pieces of three regulations that prohibited telehealth service delivery.
      - OMHSAS continues to monitor developments in BH and telehealth services and will update the bulletin as needed.
    - Collaborative capacity building initiatives.
- BH Telehealth Services for ID/A Project (slides 19–24):
  - Shannon Kojasoy provided details on the BH Telehealth Services Project.
  - Main objectives:
    - Outline recommendations to optimize use of BH telehealth with ID/A.
    - Increase awareness of Pennsylvania ID/A stakeholders.
    - Strengthen relations with Pennsylvania ID/A stakeholders.
    - Clarify and develop best practices to support co-occurring complex diagnoses for the ID/A population.
  - Discussed Process: Town Hall, survey, and focus groups' meetings.
  - Reviewed project timeline.
  - Reviewed focus group approach and topics:
    - Attendees informed of the Focus Group Form to complete if interested in participating. Link provided in the chat and feedback requested by November 9, 2022.
  - Overview of Town Hall survey:
    - Designed to gather feedback from a wide range of stakeholders tailored to each stakeholder group.
    - Aligned with focus groups questions.
    - Summary report will be provided to all participants.
    - Survey due by November 15, 2022.
- Overview on what is considered telehealth (slides 25–30):
  - Shannon Kojasoy walked through slides clarifying terminology used to receive treatment and what is considered telehealth.

- Key terminology and ways to get treatment:
  - Video communication.
  - Audio only.
  - Hybrid.
  - In person.
- What is considered telehealth?
  - Live audio.
  - Telephone.
  - Virtual check-ins.
  - E-visits.
  - Store and forward with EHR.
  - Excludes text messages, email, and fax.

- Overview of former BH Telehealth Project recommendations (completed December 2020) (slides 31–37):
  - Shannon Kojasoy walked through a summary of BH Telehealth Project recommendations from the provider and member perspective:
    - Service delivery considerations for BH telehealth.
    - Telehealth technology and security.
    - Reimbursement.
    - Quality measures.
    - Creating a culture of inclusion in BH telehealth.
  - Clarifying at close of overview that the BH project recommendations will inform the ID/A project. The recommendations just shared will not be impacted. The intent is that these are a starting point to optimize the use of BH telehealth with the ID/A population.
- Small group discussion and overview of all rooms (breakout rooms):
  - The Town Hall broke into seven smaller groups for discussion. Smaller discussions took place for approximately 45 minutes and were led by a Mercer facilitator.
  - Following small group discussions, each group shared a few key points from their discussion. A summary of the key takeaways are below.

- Self-Advocates overview:
  - Expressed strong support of telehealth and want it to continue and expand in the future.
  - Stressed the importance of choice and control, which is fostered by telehealth.
  - Emphasized that telehealth is less anxiety inducing compared to in-person services.
  - Relayed a desire for a place for feedback for telehealth appointments, specifically for technology use.
  - Suggested that assistance with technology should be offered, such as a follow-up phone calls for support, or a peer support member.
- Family and Friends overview:
  - Telehealth does not allow for psychosocial interactions and may encourage isolation for some individuals.
  - There have been successes for individuals with extremely complex needs, although specialists may function in siloes and need to have more communication with each other.
  - Individuals receiving services via telehealth should have a required in-person touch base, for example every six months.
  - It would be helpful to have someone with the individual during a telehealth visit to assist the individual and ensure the clinician is aware of issues that might not be easily visible, such as tics from tardive dyskinesia.
- BH Providers overview:
  - Compliance is difficult; there can be contradictory information from MCOs.
  - Potential for increased collaborative care between providers and specialists.
  - Many said they have learned how to incorporate telehealth into their practice but there are still challenges.
  - Telehealth may not provide individualized care/rapport of someone checking in. Risks being quick transaction to check a box.
  - Specific to family/therapist it is a mixed bag, can potentially intervene immediately when crisis occurs but there are also problems with technology, attention, quality, and privacy.

- ID/A Providers overview:
  - Assists with staffing problems, allows providers to meet the demands of their patients.
  - Allows providers to meet the needs of their patients:
    - For intimate/emotional discussions — example: sexual identity/support, easier for patients to speak because less embarrassment by having someone physically in the room. Allows for a deeper conversation.
    - For rural patients — example: psychiatry assistance available in areas where there are not local providers.
  - The ID/A telehealth platform is not as robust as the BH and medical telehealth platform. Would like to see telehealth integrated into the EMR/EHR.
  - Provides new opportunities to observe the individual in important settings such as school.
- BH-MCOs, MCOs, primary contractors, and county representatives/administrative entities overview:
  - MCOs, counties, etc. have supported providers with training, responding to questions, bulletins assistance, and providing or referring to resources on websites.
  - Although no shows have decreased, that has caused less time for providers to document notes, referrals, and required documentation.
  - Need more time to look at outcomes from telehealth. It will be very important to assess satisfaction with telehealth from the member's perspective.
  - Continued concern with access to broadband, especially in rural areas.
  - Concern with the cost of HIPAA compliant telehealth platforms.

- Next steps (slides 41–42):
  - Shannon Kojasoy thanked everyone for their participation and reminded attendees to complete the ID/A Telehealth Survey and Focus Group Form.
  - Dr. Gregory Cherpes and Jenna Mehnert Baker provided closing words; they thanked everyone for their participation and stressed their commitment to this work and engagement of stakeholders to ensure their voices are heard.

Town Hall Small Group

The notes below reflect the content of the discussion in the small group breakout rooms and are not intended to reflect a consensus or an established position.

Small Group Discussion (Breakout Room) Notes

- Self-Advocates group:
  - Use of telehealth:
    - Self-Advocates almost unanimously reported using telehealth. Participants specifically reported using telehealth for BH services, such as therapy and counseling.
  - Views on telehealth:
    - Self-Advocates almost unanimously reported that they "like" telehealth and that the benefits outweigh the downsides.
  - What works:
    - Participants in the Self-Advocates group reported a variety of strengths of telehealth.
    - Participants described the flexibility of telehealth as a benefit. Reported flexibilities of telehealth included using preferred form of communication and an easier time both getting and rescheduling appointments compared to in-person services, especially in more rural areas.
    - Participants discussed accessibility as a strong benefit of telehealth. Participants reported that it is easier for people with physical disabilities to access appointments via telehealth compared to in-person services, particularly for individuals who rely on direct service workers to get to appointments.
    - Telehealth allows people whose supports are not available (i.e., a direct service provider not showing up as scheduled) to still attend appointments.
    - The Self-Advocates group described the convenience of telehealth in terms of less time traveling to and from appointments, less money spent on gas mileage, less stress, and the ease of still attending appointments during bad weather.
    - Self-Advocates overwhelmingly agreed and strongly emphasized that telehealth provides more choice and control compared to in-person appointments. This pertains to choice of providers and taking appointments in preferred locations, such as in one's own home with their therapy animal.
    - Reduced anxiety around telehealth appointments compared to in-person appointments was also agreed upon in this group.

  - Less exposure to COVID-19 and other illnesses was also expressed as a major benefit of telehealth, particularly during pandemic surges.
  - Participants also noted that for people in rural areas, it is easier to get access to specialists via telehealth compared to in-person services.
- What does not work:
  - Participants in the Self-Advocate group reported a few disadvantages and areas for improvement associated with telehealth.
  - Technology was mentioned as a difficulty, particularly troubleshooting without support. Participants described technology as an opportunity for improvement including ideas such as having available peer supports or staff to troubleshoot technology in the moment.
  - Another idea recommended was telehealth participants being given an opportunity to provide feedback at the close of an appointment, particularly for technology issues.
  - Participants expressed concern regarding the "border barriers" surrounding telehealth and the difficulty of obtaining services from out-of-state providers. This barrier was described as "defeating the purpose" of telehealth.
  - Accessibility was also noted as having room for improvement, specifically in regards to translation services for other languages including American Sign Language (ASL). Questions also came up about the availability for telehealth for people who are Deaf and Hard of Hearing.
  - A downside of telehealth mentioned in this group was that communication can be harder in some instances via telehealth, compared to in-person services, but that the benefits outweigh this problem.
  - There was a concern noted by a participant over the licensing for telehealth providers and what can be done to ensure that only licensed providers are providing telehealth services.
- Changes since pandemic:
  - Participants noted that they had only a few instances of using telehealth prior to the pandemic, and that it was mostly services for their children.
- Future telehealth use:
  - Participants unanimously reported planning to continue using telehealth post-pandemic and some participants described their wish for telehealth to expand in the future.

- Focus groups' topics:
  - Participants hoped to be able to further discuss ways to provide feedback on telehealth.

- Family and Friends group:
  - Use of telehealth:
    - Participants in the Families and Friends group unanimously reported using telehealth with their children. Participants indicated using telehealth for BH and physical health conditions, accessing a variety of specialists for complex needs of the individual receiving services.
  - Views on telehealth:
    - The Families and Friends group reported mixed feelings towards using telehealth.
  - What works:
    - In general, participants were in favor of telehealth, but did have some suggestions for improvement in care as well as emphasizing the need that in-person care also be provided as an option.
    - One benefit of telehealth noted was the decreased need for transportation, especially when their children with more complex conditions have multiple appointments with multiple specialists.
    - An advantage of telehealth was also reported regarding geographic needs. It was noted that telehealth does allow for access to a wider range of specialists, with one participant noting that their child meets with a psychiatrist in Florida due to a lack of in-state providers that can meet their unique needs.
  - What does not work:
    - Multiple participants noted that telehealth hampered psychosocial interactions as it encourages isolative behavior and a session via telehealth cannot allow touch. It was recommended that in-person check-ins be required periodically for individuals receiving services via telehealth.
    - It was noted that telehealth is a modality and not a service, and is not the right fit for everyone. Participants discussed the concern over developing patient/client trust without meeting face-to-face.
    - Participants also felt that it might be of benefit to have a professional with the individual receiving services to help intervene, as needed, both to assist the individual and ensure that symptoms the provider may not note in a telehealth environment are discussed, for example tics due to tardive dyskinesia as a result of medication.

    - Participants in this group reported that it is difficult to find providers for individuals with complex needs.
  - Changes since pandemic:
    - No changes noted.
  - Future telehealth use:
    - Participants indicated that they would continue to use telehealth although they would like some changes such as some in-person check-ins and assistance during sessions.
  - Focus group topics:
    - Participants would like to discuss services for individuals with complex needs to determine what elements of services may be more appropriate for telehealth versus in-person as well as how services such as Cognitive Behavioral Therapy can be adapted for individuals with complex needs.
- ID/A Providers group (the two groups notes are combined below):
  - Use of telehealth:
    - All participants indicated they have used telehealth, or at a minimum have supported individuals who utilize telehealth.
    - ID/A providers reported using a variety of telehealth platforms for a wide array of services including parent/caregiver training, scheduled/routine visits, unscheduled or spontaneous appointments as well as provider assessments in which supervisors can attend appointments virtually to assess the provider.
    - Participants indicated that they typically used video accompanied with audio, although just audio (in some cases just phone calls) could be used depending on patient/client access to technology sufficient to effectively video chat (e.g., a camera, strong enough internet connection).
    - Most participants indicated that they typically use Zoom (specifically HIPAA-compliant Zoom). Other platforms discussed included Teams, Blink, personalized portals used on an individual provider basis (e.g., BirchNotes), and interactive applications/portals sponsored by larger institutions (e.g., hospitals, insurers) which integrate telehealth features into an EMR (e.g., MyUPMC).
    - Other ID/A Providers noted that they use it for supervisory and clinician-level services, as well as direct and indirect support.
  - Views on telehealth:
    - ID/A Providers reported both pros and cons of using telehealth.

- What works:
  - ID/A Providers described many benefits of telehealth including: increased transparency from integrated telehealth platforms, increased patient/caregiver autonomy, facilitation of more two-way communication, and allowed for easy gathering of feedback via anonymous feedback tools (e.g., anonymous surveys sent after appointments). One provider described telehealth as a "life changing method of treatment for people".
  - Flexibility was described as a positive of telehealth in this provider group, specifically tele-commuting, and the ability to have appointments in "unorthodox" settings such as schools and classrooms. Another benefit described was the ability of patients to attend appointments that they previously may have not been able to attend, such as when they are sick or do not have the finances to travel.
  - ID/A Providers described telehealth as positive for behavioral supports. Further, participants stated that telehealth was useful, compared to in-person services, for more intimate conversations such as sexuality supports or trauma support.
  - Telehealth was noted as supporting employee retention by allowing people to work from home.
  - A participant noted that the integration of telehealth into an EMR allowed for easier billing and was "great for things that need to be frontloaded for an ID/A provider".
  - Participant also notes that the cost of implementing these integrations is surprisingly low, especially considering how robust the platforms are. Participant attributes this to a "wider market" composed of vendors who have been in the space for a long time. Another participant noted that many medical EMRs are more advanced than BH platforms.
  - A participant noted that direct supervisors (e.g., a behavior analyst) could log in as needed to support staff or parents and to observe the patient, that there were agreements with schools to allow for observation of the patient in a classroom setting, and that they "couldn't have gotten through (the PHE) without it (telehealth)".
  - A participant noted that the ability to provide continuity of care during the PHE was invaluable, and that, while telehealth use has decreased since the "heart" of the PHE, they are still benefitting from providers being able to jump on and provide "in the moment" care.
  - A participant noted they utilized telehealth to "empower caregivers to be the driver of the intervention". They stated that many practitioners were coming from an "expert model" and "couldn't take over" through a screen, so they worked toward having the caregivers/families in a position to make decisions.

- What does not work:
  - Participants noted that in some situations telehealth proved challenging to use (e.g., in rural communities with insufficient access to a stable internet connection, or in situations where the patient/caregiver was not familiar with how to use the necessary technology).
  - Participants described telehealth as not being a one-size-fits-all approach and that it does not replace in-person services. One participant noted that it was not their favored approach to therapy.
- Changes since pandemic:
  - An ID/A Provider described increased level of in-person services and a reduction in telehealth since the peak of the PHE. Providers in this group also described an increase in sexuality services, behavioral support, and communication services through the use of telehealth. Telehealth was described as more comfortable for some patients.
- Future telehealth use:
  - Participants were in favor of telehealth, and felt that it should remain an option going forward. Many participants indicated that they would like to see continued expansion.
  - A participant also noted that they would like to see an expansion in psychiatric services as many struggle to find those services due to access issues such as living in rural settings, lack of providers, lack of public transportation, and/or lack of funds to make it to appointments.
  - A participant noted that many individuals preferred virtual care for BH, and that the field may be moving toward expanded usage of technologies such as artificial intelligence and virtual reality as a way to scale up and increase utility.
  - Some ID/A Providers noted concern regarding limitations of stakeholders/payers pertaining to their use of telehealth in the future.
  - Other providers noted they do not feel like they are notified of ODP/OMHSAS initiatives and that they need better marketing.
- Focus group topics:
  - Participants indicated they would be interested in best practices for operational standards versus clinical standards.
  - A participant shared that there was a surplus of regulations coming out, that they have struggled to abide by these different standards and that they would like to discuss how to get to a place where they were all compliant.

    - A participant stated they would like to discuss how to assess if telehealth is appropriate for patients in order to ensure that everything was held to high standards and not done simply for convenience. Other participants echoed this sentiment and added that they would like further clarity on what services were appropriate for provision via telehealth.
    - A participant stated that there is "very little guidance" from credentialing agencies, that those agencies have been slow in providing direct guidance on how to make an objective choice on appropriateness of telehealth for a patient and/or service, and that the guidance on ethical codes was needed as well. Another participant echoed this sentiment, stating that there were "guidelines but no clinical pathway", that there were no "hard recommendations", and that telehealth was being recommended, "whenever appropriate" without consensus on when it was appropriate.
    - A participant noted that they were concerned with appearing as though they were denying services as a result of holding off on providing services due to a lack of "solid guidelines to filter decisions through".
    - Participants suggested that stakeholders be included in future focus groups. Another recommendation included a group of providers and payers for discussion on what can and cannot be provided via telehealth.
    - Other ideas included best practices for operational standards versus clinical standards; how to assess if telehealth is appropriate for patients and which services; and more guidance from credentialing agencies.

- BH Providers groups (the two groups notes are combined below):
  - Use of telehealth:
    - BH Providers also report using telehealth in a variety of ways, including supervision with out-of-state providers and in circumstances when a patient is sick or in isolation due to COVID-19 and cannot attend an in-person appointment.
  - Views on telehealth:
    - BH Providers reported both pros and cons of using telehealth.
  - What works:
    - BH Providers described flexibility as a benefit of telehealth and that it allows them to service demographic areas they would not have been able to serve due to long commutes or bad weather.
    - Accessibility was noted as a positive for people with disabilities and mobility challenges.

  - Other benefits raised by this group included the ability to schedule multi-disciplinary meetings with other providers, quicker response times, less time in transit, and less mileage.
  - Increased access to specialists for areas such as Gender Identity Therapy and services for people who are Deaf/Blind was also noted.
  - Participants in this group also noted that some patients are more willing to share details via telehealth, compared to in person.
  - Positives pertaining to staff raised by this group included that telehealth supports a better quality of life for providers and increases staff retention, as well as productivity. Some also felt that it allows for better staff collaboration and compliance.

- What does not work:
  - BH Providers described the lack of personalized touch as a downside of telehealth, which can limit rapport building and trust.
  - Missing facial cues and body language, with increased reliance on tone, contributes to this.
  - Participants in this group described telehealth as not a one-size fits all approach, especially for individuals with higher levels of support needs.
  - Issues with technology were raised in this group, including that it is hard to manage multiple platforms and anticipate what is next.
  - One participant described technology as moving faster than policy and procedures and there is difficulty with compliance. BH Providers described inconsistency in expectations from the State, MCOs, clients, and care managers.

- Changes since pandemic:
  - Benefits of the changes to supervision, eliminated mileage, and transportation costs with the use of telehealth.
  - Participant agreed that compliance with supervision has increased. Some children need face-to-face care but telehealth is a helpful option when needed.
  - Participants agree that utilizing telehealth during the height of the PHE was necessary, organization has returned to “normal”.

- Future telehealth use:
  - BH Providers described their intent to continue using telehealth, while hoping for it to be more of a hybrid model, with in-person and virtual services, because telehealth cannot fully replace in-person services.

- Focus groups' topics:
  - BH providers expressed support for the planned focus groups' topics.

- BH-MCO, MCOs, primary contractors, county representatives/administrative entities group:
  - Use of telehealth:
    - Participants in this group reported they are seeing use of telehealth and view it as a positive experience.
  - What works:
    - Participants described telehealth as particularly useful for individuals with limited transportation and for people needing outpatient services.
    - One participant noted that adolescents seem to be more responsive to telehealth.
    - A participant described that telehealth is useful especially for households with multiple children.
    - A participant mentioned that no-show rates have improved with the use of telehealth.
    - Participants described telehealth as offering members more choices and flexibility.
  - What does not work:
    - A participant described that telehealth creates difficulties for viewing the "full picture" of a client or their true self and that people with ID/A may need more support on the screen.
    - Another challenge mentioned was keeping participants engaged.
    - Although no shows have decreased, that has caused less time for providers to document notes, referrals, and required documentation.
  - Support for telehealth providers:
    - Participants described supporting providers by offering regulations and answers to questions, via articles, handouts, and bulletins. Training on bill coding is offered by Intensive Behavioral Health Services, as well as information being available on websites.
    - Other participants mentioned piloting telehealth navigators and holding presentations on telehealth criteria, as well as reviewing ethics and access to telehealth.

  - Participants in this group are interested in the "BH Roadmap" would like it to be available on the Pennsylvania Department of Human Services' website.

- Utilization trends:
  - Trends are 10% outpatient health as telehealth, hybrid of telehealth and in-person, and more in-person visits.

- Barriers to telehealth:
  - Barriers described by participants included less access to telehealth/broadband in rural areas, provider consent to treatment, documentation, and HIPAA compliant platforms.

- Future telehealth:
  - Pertaining to the future of telehealth, participants expressed wanting best practices for telehealth to ensure users are getting what they need, including accessibility features like close captioning.

Appendix C
Focus Groups: Notes

ID/A Providers Focus Group One

November 30, 2022

Attendees

- **ODP:** Don Clark and Marlinda Smith
- **Mercer Team:** Rose Farrell, Shannon Kojasoy, Kathy Nichols, and Kevin Tolmich
- **Other Participants:** Five ID/A Providers

Notes

- Mercer team provided a review of the Town Hall, purpose of the ID/A Telehealth Project, project timeline, Steering Committee composition, and overview of 2020 BH Telehealth Project recommendations.
- The first half of the discussion focused on understanding current care and potential barriers to receiving telehealth services for individuals with ID/A.
  - How are you using telehealth?
    - Participants described using telehealth for therapy, behavioral and natural supports, socialization groups, and other groups such as cooking, budget courses, and mindfulness. These programs were increasingly used during the onset and peak of the Coronavirus Disease 2019 (COVID-19) public health emergency (PHE).
    - Participants expressed that while more in-person services are currently being used compared to the peak of the PHE, the telehealth services listed above are still used for individuals and families who do not want to be out in the community, are sick, or prefer telehealth.
    - It was noted that during the PHE telehealth was used for socialization groups, but that has decreased as these services are more effective in person.
    - Other uses of telehealth described by the group included psychiatric support, medication management, occupational therapy, art and music therapy, and activities to try to maintain a sense of community during isolation experienced throughout the PHE.

- Usage of telehealth (devices and platforms):
  - Participants described using a variety of devices for telehealth, including laptops, desktops, tablets, and smart phones.
  - Participants also discussed being able to provide tablets to patients through waiver funds.
  - Multiple participants described how they will use “whatever works” and whatever device is best to encourage participation.
  - Platforms used by participants included Microsoft Teams, Google Meet, Zoom, and Evolve.
  - Multiple participants reported that the ease of telehealth usage depends on the provider and the patient/consumer (i.e., it works better for some than for others).
    - It was noted that technology issues were tough at the beginning when working with residential programs, but have since improved.
  - Participants described varying circumstances with agencies making resources, such as tablets and internet access available to patients and providers.
  - One participant cited usage of Evolve as the electronic medical record and further explained that the technology infrastructure is better for BH services than for ID services (e.g., more interactive platforms).
  - Multiple participants shared that their providers/agencies were able to support individuals who do not have internet through available public programs throughout the PHE, and phones were used when internet connection was not successful.
- What has been the most useful?
  - Participants overwhelmingly described the convenience and flexibility of telehealth as a benefit.
  - Transportation, child care, and travel time were reported as more manageable because of the use of telehealth.
  - Multiple participants emphasized the usefulness of telehealth during times of crisis and when an individual needs support to de-escalate.
  - Participants explained that telehealth allows providers to have higher caseloads, as they do not have to travel as far to reach patients.
  - Decreasing rates of no shows and cancellations were noted as a key benefit of telehealth.

- What has been the most challenging?
  - Participants noted that telehealth can be challenging with users who are non-speaking.
  - Participants also noted it can be challenging for some patients to pay attention to a computer or laptop for long periods of time.
  - Other difficulties included methods of data collection, completion of forms and paperwork, follow-ups for further information, support for children's education that is out of scope, and the value of in-person services for tasks such as teaching new skills.
  - Revenue was noted by one participant as an area of difficulty, expressing that sessions are usually shorter via telehealth, compared to in person, resulting in reduced billing hours.
  - A situation was described as "today is not a good day, please call back" when working with some patients via telehealth.
- Do patients find telehealth useful?
  - Participants almost unanimously discussed how telehealth is great for some, especially for isolation during COVID-19, but not useful for all. It is not a "one size fits all" modality. It was noted that providers and individuals occasionally have different preferences when it comes to in person versus telehealth services.
  - One participant described how it can be challenging for individuals in residential settings to receive therapy services via telehealth, because privacy is limited.
- Do follow ups occur after telehealth sessions?
  - One participant explained how it is a 2023 goal to institute follow-up surveys at the conclusion of a telehealth session.
  - Other participants described how there are often check-ins before telehealth sessions to ensure people have what they need.
  - Another noted that they always try to schedule the next appointment before the conclusion of a session.

- Mercer team reviewed in-scope services and clarified that the intent of the discussion was to focus on themes, rather than specific services. The discussion focused on BH services for the ID/A population.

- The group agreed that a hybrid model of in-person and telehealth services works best.
  - Training:
    - When asked about the preparation of providers for telehealth, participants described that most are and were prepared to deliver telehealth sessions; however, some providers are better at it than others.
    - Participants described quality monitoring as helpful to ensure preparedness.
    - Participants explained that most of their training regarding telehealth occurred at the onset of the PHE and was supported by IT departments, but they do not have ongoing training. On the other hand, a participant noted that training on telehealth was always available.
    - Multiple participants stated they are using the "Vias" system for training. Others noted that they took a training through Veterans Affairs.
  - Training time:
    - Participants unanimously agreed that one to three hours of training to use telehealth is appropriate.
  - Suggestions for effective services:
    - Suggestions for effective services included an infrastructure for parent and family training, training on diabetic services, and support for troubleshooting.
  - HIPAA compliance:
    - Most participants already have HIPAA-compliant platforms enabled for telehealth services.
    - A participant explained that they had training on HIPAA compliance for telehealth and have IT support.
  - Ways to make it more appealing:
    - One participant emphasized that it would be nice to have the ability to see the whole person, rather than just "shoulders up", to be able to view non-speaking communication such as body language.
  - Use of telehealth in the future: Will usage stay the same, increase, or decrease?
    - One participant explained that they expect usage of telehealth to increase during the winter months due to weather and spikes in the PHE.
    - Most expressed that they expect telehealth to continue as a hybrid model, in which it can be used as needed. A participant suggested it be included in individual's Individual Service Plan whether they prefer in-person or virtual services.

    - Another participant expected telehealth usage to increase due to the direct service workforce shortage, especially in residential settings, and when travel and weather present problems.
    - There was agreement that telehealth usage has decreased since the beginning and/or peak of the PHE, and it is expected to continue in the way it is being used now.
  - Wishes for telehealth:
    - Participants described they hope telehealth to become more integrated and multi-faceted in the future.
    - One participant described their hope for additional training and opportunities to receive information regarding telehealth, such as this focus group.
    - Multiple participants noted a desire for uniformity in billing codes, referencing the different requirements for in-person versus telehealth services code/billing processes.
    - The issue of behavior support services came up in terms of how they are categorized and how providers have to avoid the session turning into counseling or therapy. They hoped for more flexibility on how to support patients via telehealth.
    - Other wishes included: expansion of services, increased rates and incentives for telehealth, and augmentative reality.
- Mercer reviewed the next steps and provided information on how to get in touch and information on the final report coming in March 2023.

ID/A Providers Focus Group Two

December 14, 2022

Attendees

- **ODP**: Don Clark
- **Mercer Team:** Rose Farrell, Shannon Kojasoy, Kathy Nichols, and Kevin Tolmich
- **Other Participants:** Seven ID/A Providers

Notes

- Mercer team provided a review of the Town Hall, purpose of the ID/A Telehealth Project, project timeline, Steering Committee composition, and overview of 2020 BH Telehealth Project recommendations.

- The first part of the discussion focused on current practices regarding telehealth for individuals with ID/A.
  - Participants almost unanimously agreed that they would like to see the continuation and expansion/growth of telehealth. They agreed that the use of telehealth originally came from necessity at the onset of the COVID-19 PHE, although services have now moved to more of a hybrid model of in-person and virtual services combined.
  - How are you using telehealth?
    - Telehealth used for psychiatry sessions, behavioral supports, speech-language pathology, crisis response, sexuality counseling and education, and trainings for staff, providers, and families.
    - StationMD, which provides access to doctors, specially trained in the Intellectual and Developmental Disabilities (I/DD) population, via telehealth. Staff can be reached 24/7, which is especially helpful in residential settings, and can help avoid an emergency room visit.
    - To provide access to behavior support professionals, some individuals still hesitant to go out and about post pandemic. Looking to make this a model for the agency, some individuals may have had more success with service if they had gotten services virtually.
    - When connecting with agency nurses around training and assessments.
    - Trainings online, especially helpful for residential providers and those on overnight shifts. Complex case meetings have moved to virtual format which has increased turnout.
    - Used by psychiatrists and to provide 24/7 crisis response, as can assess the situation prior to arriving at crisis site.
    - Other uses of telehealth described by the group included dance and exercise groups during the onset of the PHE.
  - Multiple participants noted that telehealth is still the preferred modality for some individuals and families due to concerns regarding COVID-19.
  - Usage of telehealth (devices and platforms):
    - Participants described using a variety of devices for telehealth, including laptops, desktops, tablets, and smart phones.
    - Participants agreed that they will work with whatever device enables an individual to participate.
    - Many of the participants use Microsoft Teams as a platform for telehealth.

- Other platforms used included: Go-To, Zoom, and Doxy.me. One participant described that while HIPAA compliant, Doxy.me is not user friendly. Another noted that Go-To does not work as well with sound.
- Multiple participants described using grant funds to obtain and distribute iPads for individuals receiving services.

— What has been the most useful?

- Participants broadly agreed that telehealth is very useful during times of crisis. It allows for a faster response of support in real-time.
- Other advantages of telehealth discussed by the participants included: convenience, efficiency, a reduction in stigma due to not having to be seen going to a BH provider's office, and access to services in areas that are more difficult to reach.
- Participants described cost savings as advantageous in terms of time-spent, resources, and fewer no shows/cancellations.
- Many participants agreed that a benefit to telehealth is that it allows providers to "meet the person where they are at" meaning that individuals can participate in telehealth from the comfort of their preferred space and environment, allow folks with anxiety to participate with fewer challenges, and encourages individuals to still participate in sessions if they are uncomfortable leaving their home due to the PHE or personal illness.

— What has been the most challenging?

- The two predominant challenges with telehealth that were discussed include technology and engagement.
- Participants reported that it can be challenging to engage participants who may have a hard time sitting still for extended periods or looking at themselves on camera (examples: individuals with schizophrenia or body dysmorphic), and for those who are non-speaking and/or have complex needs.
- Concerns about privacy were discussed and it was noted that it was easier to ensure privacy during in-person services. The importance of a hybrid model based on what the individual wants and not what is most convenient for the provider was emphasized.
- Technology challenges included Wi-Fi or connection challenges, particularly in rural areas.
- Others described that technology becomes more challenging when there is not the necessary knowledge or education on the other end of the screen to support the individual. One participant noted that they have had to overcome the "fear of technology" that some individuals experience.

- Participants also described solutions that have helped them with these challenges including MESH devices to allow for further supported Wi-Fi without cables, and American Rescue Plan (ARP) funds to help get people the equipment they need to participate.

- The second part of the discussion focused on technology use.
  - Current telehealth systems/features/platforms:
    - Participants discussed the features of the telehealth platforms they use including: virtual waiting rooms, breakout rooms, webinar features in Zoom, and video messaging (through an application Marco Polo). In order to meet the individual where they are, at times non-HIPPA platforms are used for “check-ins”. When those platforms are used no personal health information is discussed.
    - Some participants use platforms that allow for EHR connections.
    - One participant described that they are planning in the future to make improvements in privacy, use additional features such as a waiting room, etc.
    - Another participant emphasized that they use a particular platform in alignment with Business Associate Agreement (BAA) to ensure HIPPA compliance.
    - It was noted that virtual trainings were helpful for overnight staff so that they can complete necessary training without having to come into the office during a day shift.
    - A participant described that some of their telehealth work could be considered “hybrid” as the individual receiving services can have a hands-on activity to experience while joining a group virtually.
  - Technology support:
    - One provider described themselves as the only technology support person for their agency, and was brought on board during the PHE.
    - One participant explained they contract with an external provider, JAMF, to manage the iPad security system.
    - Other participants described that they are part of larger companies or umbrella organizations that have larger IT departments and support, while others described outsourcing support for technology.
    - Participants described that technology use and support applies to both internal use for staff and external use for services to individuals.
    - Participants expressed the desire for further guidance in assisting on-site in-person staff through technology issues in the moment.

  - Multiple participants described that technology can be most challenging when engaging with families and direct support professionals who may not have the experience or skills to trouble shoot.

- Cost and payment:
  - Multiple participants described using grant opportunity and ARP funds to help pay for telehealth technology.
  - Two participants explained that cost have been incurred creating Zoom professional accounts, which allow for sessions longer than the 40-minute free version.
  - Other costs include licenses for platforms, Augmentative and Alternative Communication (AAC) devices, technology security, and supporting iPads. One participant noted that they have been able to use waiver funds to support AAC and Assistive Technology (AT).
  - Participants described some costs as not going away, such as licenses for platforms and technology support costs.
  - Cost savings have occurred through downsizing physical office space, decreasing gas mileage and wear and tear on vehicles. One participant described telehealth as “improving staff quality of life”.

- Ways to support participation:
  - Multiple participants described that they have not had to utilize many accommodations such as translation services, live captioning, etc.
  - Others discussed using translation services for ASL and other languages such as Korean.
  - One participant described their hope for accommodations to improve and expand so they can further support non-speaking individuals, as hearing AAC devices virtually can be a challenge.

- Provider agreements and administrative burdens:
  - It was noted that when equipment is provided to an individual, there is an agreement that includes information such as the equipment is a loan, not a gift, and what appropriate uses are for the device.
  - It was also noted that provider agreements need to have all necessary agreements checked to ensure security. This places some administrative burden on the provider/organization to manage and track compliance.

- The last part of the discussion focused on best practices and operational standards.
  - Best practices for telehealth:
    - A majority of participants agreed that telehealth is not a one size fits all system. Some individuals are able to meet their goals virtually while others need in-person supports to do so.
    - Goals should be defined and data used to determine and assess telehealth for each individual.
    - Ensure the individual is comfortable in their setting, assess if staff are in the room, and that communication needs are met. Communication needs and privacy needs must be met and taken into account when using telehealth.
    - Telehealth should be used for the benefit of the individual receiving services, not the convenience of the clinician or provider.
    - It would be advantageous to have one platform that could do everything (i.e. be HIPAA compliant, allow for data collection, centralized tools).
  - Best practices for telehealth for individuals with complex needs:
    - Participants explained that for individuals with more complex needs, telehealth can be particularly useful in times of crisis so provider can get a full picture.
    - One participant recommended that at the start of services, there should be open communication and a plan for how telehealth is going to be utilized for the particular person.
    - It is recommended there is a meet and great with families and friends, care team, etc. to share information about telehealth, how it can be used, and why it can be helpful. This is especially helpful for individuals with complex needs but a best practice for all individuals with ID/A.
  - Determination of telehealth usage:
    - One participant described their usage of a telehealth assessment to determine if the individual is appropriate for telehealth, including areas such as communication and privacy, including whether there is a private and safe space in the home and whether or not a support person will be in attendance during services.
    - Another participant advocated against the idea of the first-appointment being in person, as some individuals would not get services at all if they had to show up in person for the first appointment.
    - Others described that there must be an evaluation of barriers to the person receiving telehealth before moving forward.

    - It was noted that due to provider shortages there may not be an in-person option for services, for example if the closest psychiatrist accepting patients is three hours away.

  - Models of telehealth:

    - Participants described learning from each other as a great opportunity to find best examples of telehealth. They noted that there is no perfect model, and they hope to keep learning from each other.

    - One participant noted there is a great model for smart home and total technology under development in Tennessee that would be interesting to explore further.

    - Participants expressed they will continue to pivot as further bulletins and information is made available. There is a desire for consistency to minimize changes in the future.

- Mercer reviewed the next steps and provided information on how to get in touch and information on the final report coming in March 2023.

Family and Friends Focus Group

January 18, 2023 and January 19, 2023

Attendees

- **Mercer Team**: Rose Farrell and Shannon Kojasoy
- **Other Participants:** Twenty Family and Friends

Notes

- Welcome and introductions.
- Mercer provided overview of the ID/A Telehealth Project.
- Summary of feedback from two meetings (Pennsylvania Family Network and JCHAI), 20 attendees including, friends/supporters of individuals with ID/A and parents of young adults, transition age individuals, and adults with ID/A.
- Feedback is provided by the friend or family member in reflection of their individual with ID/As experience with telehealth.
- The focus group questions were organized in two themes: understanding the stakeholder experience and BH services for the ID/A population.

Understanding Stakeholder Experience: Current Care and Potential Barriers to Delivering/Receiving Telehealth Services to Individuals with ID/A.

- What types of telehealth services have you had experience with?
  - For psychiatry, BH, talk therapy, behavior counseling, vision therapy, speech therapy, occupational therapy, and medical appointments.
    - Specific services included Friendship Circle meetings, CAP services, and Carousel Connections.
  - Experience using computers (desktops and laptops), phones, and tablets. A variety of platforms were discussed including Zoom, FaceTime, Microsoft Teams, Google Meet.
  - A couple individuals reported their individual with ID/A does not use telehealth.
  - An individual reported their individual with ID/A does not have a smartphone, but uses a laptop at home when accessible.
- What are the benefits of receiving services via telehealth?
  - Convenience, accessibility, uses less time in a day, less exposure to germs, and being able to stay home when sick.
  - To replace in-person appointments that would otherwise have to be cancelled due to illness or bad weather.
  - Benefits of telehealth pertaining to convenience included: less time traveling in the car and the absence of spending gas money, dealing with parking, getting into medical buildings, and navigating hospitals. These are true especially if an individual is having a hard time, “meltdown,” or challenging behaviors.
  - Many families and friends explained that telehealth allows their “person” to stand up and move around during the appointment, which is important and beneficial, particularly for individuals with Autism.
  - Participants explained that telehealth is most beneficial when the provider is experienced and uses it successfully.
  - Participants also detailed that some therapists are just “better” at providing telehealth compared to others, meaning they are more engaged, try to see the “whole person,” and bring a bit of their life into the appointment, such as showing the individual receiving services items from their office.
  - Other benefits of telehealth included being able to take appointments while on vacation and having their adult children be able to take their therapy appointments while they are at work, meaning “less running around”.

  - Examples of successful telehealth use:
    - An individual described that the person she supports had great success using telehealth for vision therapy as it made them less self-conscious, more comfortable, and less pressured. They were able to make great progress using telehealth because of this. It also relieved caregiver stress.
    - An individual with Autism uses telehealth for behavioral support on the phone two times per week. It works well for them. Engagement can vary depending on the day but it works for them.
    - In one case, an individual was able to develop relationship with peers with telehealth groups for socializing and this model worked better for them compared to pre-COVID-19 times.
    - For some individuals, it is easier to open up emotionally via telehealth as the person can be more comfortable in their own space through a screen.
    - An individual shared an experience where a particular provider made telehealth very successful for the person receiving services. The provider set up online strategies and visuals to help the individual with their behavioral goals at home. The visual support was helpful and also allowed the provider to collect data online.
- What are the challenges in receiving services via telehealth?
  - Multiple participants explained that the challenges of telehealth can depend on the individual provider.
    - Example: During telehealth sessions with a particular provider, the provider had a hard time with technology, was "fiddling with volume and buttons," and not looking at the screen. This made it challenging for the person receiving services.
    - Another individual explained that particular providers may not be as engaging via telehealth, and it can depend on provider personality.
  - Examples of challenges with telehealth:
    - One individual had a difficult time with their sole experience of telehealth, and would prefer not to use it.
    - An individual had a hard time with telehealth groups and did not enjoy participating and usually kept their camera off.
    - In another instance, a participant described that the individual receiving services needs the in-person contact because they already experience isolation. This person had trouble engaging in telehealth, particularly in groups, and had trouble staying focused.

    - Further challenges included that the individual receiving services can get easily agitated during telehealth appointments.
  - Multiple participants explained that telehealth became more successful over time after more use.
- Do you (or the individual you support) prefer services via telehealth or in person?
  - Participants expressed that it depends on the type of appointment and the provider.
  - Participants described their preference for telehealth services for routine appointments, or for shorter visits such as reviewing test results.
  - An individual described how the experience of telehealth varies between their two children.
    - One teenager with Down Syndrome had positive experience with telehealth.
    - Their other child had more challenges with telehealth. This child had more social, emotional, and BH challenges.
  - A parent explained that their adult child with Autism has had more success with telehealth once it was part of their routine, rather than something new to learn.
  - One participant explained that the benefits and challenges of telehealth are a bit of a dance, where there has to be a balance between getting out and about and practicing social skills, while also experiencing the flexibility and convenience of telehealth. This feeling was supported by others.
  - In one case, the experience of telehealth during the onset of the pandemic make an individual adverse to telehealth in all instances.
- Is there a difference in quality of services provided via telehealth and in person?
  - An individual explained how telehealth for behavior therapy can be particularly challenging and that it is better in person so the provider can better see and understand behaviors.
  - Another person explained that therapy appointments are better in person because it allows for more connection. This differed from another person's experience, where an individual was more comfortable via telehealth because they feel less "put on the spot".
  - Telehealth quality varies by the provider and what is most important for the individual receiving services.
  - Multiple participants explained that a "hybrid" mode is best for them, having some appointments in person and some via telehealth. In a few cases, individuals had more success with telehealth when they already knew the provider in person.

BH Services for Telehealth in Pennsylvania for ID/A Population

- Are providers adequately prepared to deliver telehealth services?
  - A participant described their individuals experience with a community support program (Schuylkill County Cares program) that did a great job via telehealth because there was a concerted effort from staff and the staff training really made a difference. They described how this created better engagement and participation.
  - Participants described that when providers are not prepared to handle technology, it is challenging.
  - An individual explained that it not always easy to access technology, and that providers assume that everyone has access. This is especially true when providers prompt users to use an application, but they do not have a smart phone or tablet.
- Are there any suggestions to help them provide services more effectively through telehealth?
  - Participants encouraged further training for providers.
- Have you received any training and/or support specific to using telehealth?
  - Participants noted that Vision for Equality had a training on technology and computers that was very helpful.
  - Most participants have not received training to use telehealth.
  - Individuals discussed how it is not always easy to access support, such as funding through waivers for assistive technology.
  - Pennsylvania Family Network is hosting a three-month training on technology in the fall 2023.
- What would help you feel more prepared to receive services through telehealth?
  - Participants thought further training would be helpful.
- How can an individual be assured of privacy during a telehealth session?
  - Privacy was a concern for participants. Participants described situations where providers handled privacy well:
    - One provider asked the person receiving services if it was okay that they were there in the room with them.
    - Another provider described at the beginning of each session that they are alone in their house/office and nobody can hear them.
    - A participant noticed that Geisinger handled privacy well.

    - Another individual described how both in person and via telehealth, that the provider asks the parent if they would like to join the last few minutes of the session, but always asks for the approval of the individual receiving services first.

  - Participants felt more secure and assured when privacy was acknowledged.
  - A participant explained the challenge of privacy at their house, making it difficult to have private telehealth appointments.
  - Other participants described that their privacy concerns vary based on the type of appointment, dependent on the sensitivity of the topic.
  - A privacy concern came up regarding how it might be harder for some young adults to talk about particularly sensitive topics via telehealth, such as parent child conflict.

- Do families and friends need to assist the individual receiving services?
  - Participants supported individuals receiving services in a variety of forms. Some needed to provide full support and others provided support only if needed.
- Do providers ensure whether the individual receiving services wants them to be present for services?
  - Participants explained that some, but not all, providers confirm their presence is okay for services.
- If the individual you support is not using telehealth right now, what might make telehealth services more appealing for them?
  - Participants noted a variety of ways telehealth could be more appealing including: privacy and quiet background settings, having some medical equipment at home, and having providers trained more extensively, trained particularly in online tools such as Jam Board.

General Feedback

- A participant inquired about the grouping of Intellectual Disability with Autism. They expressed their desire that the differences in need between these families is documented in notes and in future recommendations. They expressed gratitude for the services for ODP provides, but expressed concern over the two groups being “lumped together”.
  - This was supported by other participants. Support was given to the suggestion of individualization being important when discussing benefits and challenges of things like telehealth.
  - One participant reiterated how telehealth was different for their two children with two different diagnoses, using the example that their child with an Intellectual Disability did not experience the same isolation challenges throughout the pandemic compared to their child with more social-emotional related challenges.

- Telehealth appointments can require that the family/friend is more present during the appointment to assist the individual in staying engaged.

Self-Advocates Focus Group

January 18, January 23, and January 25, 2023

Attendance

- Mercer Team: Rose Farrell and Shannon Kojasoy
- Other Participants: Forty-four Self-Advocates

Notes

- Welcome and introductions.
- Mercer provided overview of the ID/A Telehealth Project.
- Summary of feedback gathered from three meetings (SAU1, JCHAI, and Spectrum Friends) — approximately 44 attendees overall.
  - SAU1 and JCHAI included a mix of coordinators, power coaches, direct support, and self-advocates.
  - Spectrum Friends was primarily self-advocates with Autism.
- The focus group questions were organized in four themes: Basics, Independence, Accommodations, and Communication.

Basics

- How have you accessed telehealth services?
  - Participants had experience using computers (desktops and laptops), phones, and tablets. A few noted a preference for desktop.
  - Participants noted that in addition to social groups, they have used telehealth to connect to nutritionists, yoga classes, cooking classes, therapy, and psychiatry.
- What is most helpful about telehealth?
  - Many participants described benefits of telehealth including convenience, accessibility, less exposure to germs, and being able to stay home when sick or anxious.
  - Telehealth allows more flexibility with appointments and permits easier access to support animals.
  - ASERT was noted as a program that also offers a support line to assist their patients when accessing telehealth.

- Helps lower anxiety around appointments and especially for those people who do not feel comfortable wearing a mask.
- Have appreciated option for online/telehealth check-in appointments.
- It is good to know it is there in case of an emergency.
- Provides access to ICAP, an adult autism group.
- Able to connect when traveling or away from home.

- What are the challenges in receiving services via telehealth?
  - Many participants noted technical challenges getting online and connected to the appointments.
  - Quite a few participants noted they prefer in-person appointments as the emotional connection is difficult via telehealth. Do not like the distant feeling of telehealth "miss hugs".
  - There was also a general sentiment that traveling to an appointment and having that time in person with others was very positive.
  - With new providers, telehealth does not allow the provider to get to know the "full picture" of the person they are engaging.
  - Individuals with a difficult time speaking (speech clarity) have increased challenges with telehealth, often being requested to repeat themselves multiple times.
  - Email links and sign on information difficult to use for appointments. Often information sent to multiple devices; i.e., text link for meeting on desktop.
- Do you want your use of telehealth to increase, decrease, or stay the same?
  - Many participants mentioned they do not use it a lot and want to use less, prefer in person.
  - Some noted they would continue to use same as now, some in person and some telehealth depending on type of appointment.
  - Others noted it will continue to depend on the appointment, for example therapy works well via telehealth but other appointments are better in person.
- Does telehealth help support your independence? If so, in what ways?
  - It increases choice of provider and allows communication via chat, text, etc. Which is helpful for those people who prefer not to speak.
  - Has allowed a continuation of care with providers when the person has to move their home.
  - Has allowed for more options of therapists as location is not a barrier.

  - Was a great tool when a participant moved to another state, was able to remain connected with social groups. Also was able to meet new community before arriving in new state.
- Have you received the accommodations you need?
  - Would like it to be more personalized. It can feel like they are going through a check list.
  - It would be nice if there was more support to navigate the internet.
  - Preference for vocal communication but like to see things in writing.
  - There is not a lot of privacy.
- Did you receive any training to use telehealth?
  - Majority of respondents noted they were self-taught. Helps that it is similar to FaceTime.
  - Some parents had assisted initially.
  - Many noted it would be nice to learn more about the features and tools.
  - Zoom is very familiar but took a while to learn. Learned through trial and error.
- What would help you feel more prepared to receive services through telehealth?
  - If the computer could recognize voices better.
  - Telehealth is often accompanied by staff, if there was no staff then it would be difficult to access. However, with staff there is less privacy.
  - Telehealth is often lonely with limited privacy.
- What could be better with telehealth?
  - Not a lot to improve.
  - Missing face-to-face interactions, cannot fix that problem.
  - Make it more personable.
  - Ensure there is more time to use the devices and to respond to questions. The technology can slow responses.
  - Make sure that everyone has access to computers. In residential settings the computers are often for staff only.
  - More engagement from the provider so attentions does not wain.
  - No technology problems, no errors.

- If it was provided for free.
- More help getting connected.
- If it was easier to get connected with fewer steps.
- If there was one system for telehealth.

- Anything else we should know about telehealth?
  - One person shared how much they enjoy telehealth and will continue to use it. It minimizes exposure to illness and allows people to attend their own appointments even when they do not feel 100%.
  - The two factor authentication is very complicated and difficult to navigate.
  - There are sometimes problems with billing and charges over telehealth. Worried to use because of fees.
  - Participants had a short discussion on electronic signatures and informed consent, participants spoke about not liking this as it is not always clear and makes them feel deceived. They noted that they are not always sure what/or when they are signing. Appears to be some distrust/fear around using telehealth and trusting the technology.

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