



The Person Experiences Interview Survey Administration Manual (PEIS)

Version 1.8

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Background and Purpose of the PEIS

The Importance of the Perspectives of Persons with IDD (Intellectual and Developmental Disabilities)

It is important that persons with IDD have a way to give input about their experiences with their mental health services and providers. We often get the perspectives of family members and caregivers. The perspectives of persons with IDD who use these services are important and can also be different from those of their family members and caregivers.

- The Person Experiences Interview Survey (PEIS) is a self-report tool to evaluate mental health service experiences from the perspective of service recipients with IDD. The PEIS allows for the experiences of service users to be considered when making treatment decisions. It can also be used in research to learn about trends in service experiences.
- The goal is to provide all service recipients with IDD ages 12 and older with the opportunity to complete the PEIS, regardless of their communication preferences and type of disability. It's important to not make assumptions about who can and cannot answer the questions. Some persons with IDD may not have experience sharing their perspectives and completing self-report tools such as the PEIS. They may need more enhanced support and additional opportunities to practice self-reporting.
- Guidelines are provided to assist in making the PEIS accessible to as many people as possible. It is important to have familiarity with the questions, guidelines, and tools prior to conducting the PEIS.

What is a Patient Reported Experience Measure?

- Patient reported experience measures (PREMs) are a mechanism for people receiving services to provide feedback about their mental health service experiences.
- The Person Experience Interview Survey (PEIS) is a PREM for people with IDD about their mental health service experiences. The PEIS does not seek feedback about specific mental health providers, but rather, the overarching service experiences across all mental health providers (prescribers, therapists/counselors, crisis response teams).

History and Background

- The PEIS is based on the Family Experiences Interview Survey (FEIS). The FEIS, developed by Tessler and Gamache in 1995 was adapted by Dr. Joan B. Beasley in 1997 to capture the service experiences of family caregivers for people with IDD-MH as part of the first research on the START model, published in 2000.
- The PEIS was developed with direct input from persons with IDD and mental health service experiences, family members of individuals with IDD, and along with mental health professionals.
- The PEIS gathers information on similar topics as the FEIS, but modifications were made to ensure accessibility for service recipients with IDD. There are fewer questions on the PEIS. For more information, refer to **Appendix E: Alignment of PEIS Questions with FEIS Questions**.
- The PEIS uses the same response choices as the FEIS. This makes it possible to identify similarities and differences between a person and their family member's experiences, when also using the FEIS.

Who Can Administer the PEIS?

- Clinical interview skills and knowledge are needed to administer the PEIS. Examples of professionals who may have these skills include but are not limited to social workers, mental health outpatient providers, and occupational therapists.
- It is important to be familiar with the PEIS and associated resources (see appendices) prior to administering the PEIS.
- Those who administer the PEIS should have resources available to assist the person if they become upset during administration.
- A trauma-informed approach to administration incorporates empathy, validation, a genuine interest in the person you are meeting with, and the use of active listening skills so that you can react promptly to signs of distress. These strategies will help you build rapport and trust with the person, increasing your chances of gathering accurate information needed to address their concerns.

When to Administer the PEIS

- Do not administer the PEIS to persons experiencing an acute crisis.
- Before administering the PEIS you will need to gather information about mental health providers, services, and significant events within the past year from records, family, and other caregiver(s). You should also ask the family or caregiver(s) if there are ways to help the person recall events and people from the past year, such as a calendar or pictures.
- Any historical information you gather about mental health services and providers will be helpful references during the administration of the PEIS. Accurate reporting of mental health providers and services from the past year ensures the information being gathered is relevant and captures current service gaps and barriers.
- Allow time for rapport-building and information gathering prior to administration of the PEIS.
- The PEIS can be re-administered periodically to evaluate changes people's experiences and identify areas for improvement. The PEIS can also be re-administered at the conclusion of treatment.

Appropriate Ages for the PEIS

- The PEIS was designed to be as accessible as possible for people across the life course.
- People ages 12 and older should be given an opportunity to complete the PEIS. Youth may not have experience sharing their perspectives and completing self-report tools such as the PEIS. They may need more enhanced support and additional opportunities to practice self-reporting.

Language

- The PEIS is currently available in English and Spanish.
- Interpretation services are needed to administer the PEIS in languages other than English and Spanish.

Eight Steps to Administering the PEIS

Once you have familiarized yourself with the PEIS and the tools to administer it, administrators must create an environment in which the person feels comfortable sharing their honest perspectives of their mental health providers and services. Getting ready to administer the PEIS (Steps 1-2) and the following the Instructions for Administering the PEIS (Steps 3-7) will help ensure a comfortable and successful administration process.

Getting Ready to Administer the PEIS

1. It is recommended that a caregiver or other supporter is present during the administration

- Including the caregiver or other supporter in the PEIS interview is a joint decision made by the person with IDD, person administering the PEIS, and the caregiver. Caregivers can help create a comfortable and supportive environment. Caregivers may also help the person remember specific events with mental health providers and services that happened in the last year.
- There will be times when the person with IDD prefers to participate in the PEIS without a caregiver or other supporter, and this is also acceptable.
- It is important to remind everyone that the purpose of the PEIS is to provide the person being interviewed with the opportunity to share their own experiences with mental health providers and services.

2. Identify accommodations and support needed to administer the PEIS

- Prior to administration, identify individualized accommodation's and support that can help persons with IDD complete the PEIS.
- Many accommodations can be provided during the administration of the PEIS. This includes, but is not limited to:
 - » Responding by writing or pointing to the response scale choices.
 - » Program the PEIS response choices and symbols into an Augmentative and Alternative Communication (AAC) device
 - » The **Appendix G PEIS Response Choice Cards** are helpful for many persons, but especially those who use the Picture Exchange Communication System (PECS)®
 - » Administering the questions over 2 or 3 shorter sessions
- The PEIS questions and response choices should not be changed, however, the administer can provide support during administration (see Step 8, below).
- The "Introduction to the PEIS Video" includes closed captioning, but not audio descriptions. If audio descriptions are needed, the administrator can pause the video and provide a description, or provide the instructions for completing the PEIS without the video.
- **Have a plan in case someone is having difficulty:** During administration, pay attention to verbal and non-verbal cues to assess for signs of difficulty. If someone is upset or overwhelmed, stop administering the PEIS. Let the person take a break and assist them with using their coping strategies (deep breathing, taking a walk, listening to music, coloring, etc.). Plan another visit to complete the PEIS if it cannot be completed.

Instructions for Administering the PEIS

Steps 3- 6 are reviewed in the “Introduction to the PEIS Video.” This video is designed to be easy to understand and engage. You can choose to show the video before administering the PEIS. If you have experience administering the PEIS, you may choose not to show the video and complete steps 3-6 directly with the person receiving services.

The “Introduction to the PEIS” Video is available in [English](#) and [Spanish](#).

**“Introduction to the PEIS” Video
(English)**



**“Introduction to the PEIS” Video
(Spanish)**



3. Explain the purpose of the PEIS

- The person being interviewed may feel more comfortable sharing their perspectives when they understand the purpose of the PEIS. Provide a brief but clear description of why they are completing the PEIS and how the information will be used. This includes explaining who will or will not find out about the specific information shared during the PEIS administration.
- “Wrap up” your dialogue with a reminder of how you will use the information shared.

Example Directions Script: Our job is to help you get the most out of your mental health services. I need to know from you what is helpful, and what needs to be better in order to help you. My job is to listen to you and do what I can to help your mental health providers improve services if needed. What you tell me today won't be shared with your providers. If you would like me to share with other people, like your family, we can do that together.

4. Establish the 1-year recall period.

- **During administration, it is required to use the PEIS Administration Support Worksheet (Appendix B)**, which includes a place to list the important events that happened to the person during the past year.
- The PEIS asks the person about the mental health providers and services they received over the **last year**. Before administering the PEIS, use information from records and family interviews to write down key events that the person with IDD-MH would remember from the past year. This could include birthdays, hospitalization, holidays, the start or end of programs or services, and other events that impacted the person's well-being e.g., recent move, new job, loss of a family member. Review these dates and key events with the person.
- Remind the person (Step 6) of the 1- year recall period. This is especially important to remind persons who, over the past year, had multiple services or providers, a significant life event, or a crisis. It's likely that the person will respond thinking about the most recent experiences, and that is okay. If the person references providers and services from more than one year ago, direct them to the current list of providers and services (see Step 5).

Example Directions Script: When you answer the questions today, you should think about the last year. What's today's date? [pause]. Great! Now, think about one year ago- what's that date? [pause]. Now think about something that happened about 1 year ago. Can you tell me about something that happened around that time? [pause] Great! To help you remember the things that happened during the past year, you can think about the last four seasons, your last birthday, and your favorite holidays.

5. Review of mental health providers & services

- During administration, it is required to use the PEIS Mental Health Services & Providers Infographic (Appendix C). Administrators should review the definitions and examples of mental health providers and services with the person.
- Remember, the PEIS questions are about overall experiences with mental health providers and services, as defined in the PEIS Mental Health Services & Providers Infographic. Questions are not intended to evaluate a specific mental health provider.
- During administration, it is required to use the PEIS Administration Support Worksheet (Appendix B), which includes a place to list the person's mental health providers and services. The administrator can work with the person to write down the names of their mental health providers and the specific types of mental health services they received over the past year. Any information gathered from family members and/or clinical documents should be reviewed with the person to ensure they remember the mental health providers and services that were identified. This information can be written at the bottom of the PEIS Support Worksheet (Appendix B).

Example Directions Script: Think about the mental health services and providers you had during this past year. I made a list of some of the mental health services and providers you've had. Let's review the list together and see if there is anything else to add. Remember, when you answer these questions, you are going to think about the providers and services on this list.

6. Teach how to use the PEIS response choices.

- During administration, it is required to use the PEIS Administration Support Worksheet (Appendix B), which includes a visual PEIS response scale.
- The PEIS uses four response choices to evaluate experience and satisfaction with services: "All that I want or need;" "Some, but not as much as I want or need;" "Very little;" and "Not at all." The PEIS response scale includes a few additional features to help the person pick the response choice that accurately reflects their experience:
 - » A colored response scale with response choices indicating satisfaction with services in green and response choices indicating less satisfaction with services in red.
 - » Response choices arranged along a straight, vertical line with responses indicating more satisfaction with services at the top of the scale and those indicating less satisfaction with services at the bottom of the scale.
 - » Symbols to show the responses for more satisfaction with services (thumbs up) and less satisfaction with services (thumbs down, "x").
- Before asking the PEIS questions, give the person a chance to practice selecting a response choice to an example question about doing their favorite activity. Continue to practice or provide explanations to ensure the person uses the response categories appropriately. Use the word "choices" instead of "answer" to remind the person that their choice is based on their thoughts and feelings and there is no correct answer.

Example Directions Script: *Today, you will answer questions about your mental health providers and services. For each question, you will be able to pick one of four choices. Here is a picture showing the four choices. They are: "All that I want or need;" "Some, but not as much as I want or need;" "Very little;" and "Not at all." All questions are answered using these four choices. The color green and the thumbs-up are matched with choices that mean your mental health providers and services are meeting your needs. The color red and the thumbs down or "x" are matched with choices that mean your mental health providers and services are not meeting your needs.*

Let's practice using these choices before we get started. What is one of your favorite activities to do? How often do you get to do that activity: All that you want or need; Some, but not as much as you want or need; Very little; or Not at all?

- » How often do you usually do the activity?
- » Would you want to do the activity more? What response choice is the best match with that?
- » Are you happy with how often you get to do this activity now? What response choice is the best match with that?

7. Dialogue about each PEIS question

- **Appendix A PEIS Administrator Form** includes all PEIS questions. The administrator can use this form to record responses to each question and other information about the administration of the PEIS. ***This form is not intended for use by respondents.***
- The PEIS is an opportunity to have a dialogue with the person you are interviewing. It is not a ‘checklist’ of questions, but an opportunity to learn more about their experiences with mental health services.
- One approach to encouraging dialogue is to ask the person to **“think out loud”** when answering each question. Thinking aloud can also help the person think through the question before they pick a response.
- Using the information gathered through dialogue, the administrator can support the person to pick the response choice that best matches their experiences.

Example think aloud prompts:

- *Why did you choose “Some, but not as much as I want or need” (or other response choice)?*
- *Tell me more about when your “services changed to meet your needs” (or another item)?*
- *Can you give me an example of when your “providers gave you a chance to make decisions about your treatment” (or another item)?*

Example response choice prompts:

- *Did this happen as much as you wanted, or would you like to have this more? What choice matches how you feel about that?*
- *It sounds like this didn’t happen very often- what choice matches how you feel?*
- *It sounds like this really worked well for you- what choice matches how you feel?*
- *If you met with [provider] every two weeks, was that good for you, or did you want to meet more or less often? What choice matches how you feel?*
- *If you feel like [provider#1] listens to you “all” of the time, but [provider #2] listens to you “very little”, what choice would match how much your providers usually listen to you?*

8. Provide support to help the person understand each question

- During the think aloud dialogue, you may realize that a person is thinking of experiences that may not match the meaning of the question.
- **If someone needs additional support to understand the question:**
 - » Read the provided 'example' for each question (**Appendix D: PEIS Questions & Examples**), and help the person identify experiences like the example.
 - » Replace the word "provider" or "service" in the item with the name of the person's provider(s) and services(s). For example, the question "How often did your mental health providers help you with something you were worried about?" would be revised to "How often did Dr. Gonzalez and Ms. Tonya help you with something you were worried about?" You may also refer to photos of the person's mental health providers during administration.
- **If someone needs additional support to understand the response choices:**
 - » If a person has difficulty selecting from the four response choices, break down the process of choosing the response. First, help them determine if their experience overall was good, bad, or mixed. Or ask them if the situation described in the question happened or did not happen. Next, use that information to help them identify the response choice that best matches how they feel. For example, if the overall experience was mixed, then direct them to consider the response choices "Some, but not as much as I want or need" or "Very little."
 - » Use the colors or symbols to talk about their experiences, then link them to a response choice (e.g., *"Is that all green, all red, or green and red mixed together?"*).
- **I don't know/ Did not answer responses:** Appendix A PEIS Administrator Form includes the option "I don't know/did not answer" that can be checked if the person is unable or unwilling to answer the question. Before checking this response, make every effort to elicit a different response. Persons may have different reasons for initially answering "I don't know," including:
 - » This is the first time the person has thought about this specific question/topic
 - » The person is having trouble choosing between response categories
 - » The person is afraid their answer will seem "wrong"
 - » The person doesn't want to talk about it
 - » The person needs more time to think.

When this occurs, pause and provide some more time, and use the prompts provided in Step #7 to help the person think through their response.

How to use the information from the PEIS

- Reporting requirements: As with any clinical interview, it is important to comply with mandatory reporting requirements.
- Responses from the PEIS should be reviewed by the team to develop a comprehensive plan to address unmet needs and concerns. For more information, refer to Appendix F: Strategies to Address MentalHealth Service Experiences.

Person Experiences Interview Survey (PEIS) Version 1.7 (01/21/26)

The PEIS was developed as part of the research study “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities” funded by the Patient Centered Outcome Research Institute (Grant #14MN50).

[Appendices \(English\)](#)

[Appendix A: PEIS Administrator Form v1.5](#)

[Appendix B: PEIS Administration Support Worksheet v1.0](#)

[Appendix C: PEIS Mental Health Providers & Services Infographic v1.0](#)

[Appendix D: PEIS Questions & Examples v1.1](#)

[Appendix E: Alignment of PEIS Questions with FEIS Questions v1.0](#)

[Appendix F: Strategies to Address Mental Health Service Experiences v1.0](#)

[Appendix G: PEIS Response Choice Cards v1.0](#)

Appendix A: Person Experiences Interview Survey (PEIS) Administrator Form

Respondent ID			
Date of Interview:		Length of Interview:	
Name of Interviewer:			

The PEIS was developed as part of the research study “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities” funded by the Patient Centered Outcome Research Institute (Grant #14MN50).

The PEIS and this form should only be used with permission from the PEIS authors. For more information, please contact: Joan B. Beasley, PhD at joan.beasley@unh.edu and Jessica Kramer, PhD at Jessica.kramer@php.ufl.edu

Interviewer Instructions:

The PEIS questions should only be answered by the respondent, not a proxy/informant (e.g., parent, guardian, staff).

Remind the respondent that the goal of administering the PEIS is to learn more about their experiences with the mental health service providers and services. The information will be used to improve mental health services. Assure the respondent that the information they provide will remain confidential, and there are no right or wrong answers.

This form is not intended for use by respondents. When administering, it is required to use “Appendix B C PEIS Administration Support Worksheet” and “Appendix C PEIS Mental Health Providers & Services Infographic”.

The [Introduction to the PEIS video](#) teaches respondents how to complete the PEIS (Password: “AC” all caps)



Interviewer Name: _____

Did anyone provide support during the PEIS interview (excluding the administrator):

- ☐ None ☐ Parent/Stepparent ☐ Relative (other) ☐ Staff person
- ☐ Case manager/Service coordinator
- ☐ Other: _____

Section A: Person Evaluation of Mental Health Services

Interviewer Instructions:

Read each question as it is written and use the “PEIS Administration Support Worksheet” and “PEIS Mental Health Providers & Services Infographic” during administration. Support respondents answer each question by: 1) encouraging them to think aloud as they choose their response, 2) providing examples (see Appendix D “PEIS Questions & Examples”), and 3) using the name of their specific mental health service(s) or provider(s) in the question. All questions refer to experiences with mental health services & providers over the past year (12 months).

In the past year.....

[1] Not at all	[2] Very little	[3] Some, but not as much as was wanted/needed	[4] All that was wanted/needed
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Practice: Think about an activity you like to do. How much did you do that activity over the past year?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A1. How much do you meet with, talk to, or message with your mental health providers?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A2. How often did your mental health providers help you with something you were worried about?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A3. How often did you get to say what you want or need for your mental health services?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A4. How often did mental health services change to meet your needs?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A5. How often did mental health providers ask you how much you like your mental health services?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A6. How often did you get to choose the person who provides your mental health services?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A7. How often did mental health providers give you a chance to make decisions about your treatment?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

In the past year....

A8. How often were you satisfied with your family member's involvement in your treatment?

If you don't have a family member involved, you can think about a friend or other support person who is involved in your treatment.

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A9. How often were mental health services provided at a time and a place that was easy to get to?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A9 (b) What made it hard to get services? (Check all that apply)

- ☐ Services were too far away ☐ Hard time getting transportation to services ☐ Could not get an appointment at a time that worked with my schedule

☐ Other, please describe: _____

A10. How often did you get all the mental health services you needed?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A11. If you had a mental health crisis, how much information did providers give you about how to feel better?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A12. If you had a mental health crisis, how much information did you get about who to call?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A13. If you have a mental health crisis, how much help can you get on nights or weekends?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A14. How often were you satisfied with your mental health services?

- ☐ Not at all ☐ Very little ☐ Some, but not as much as I want or need ☐ All that I want or need ☐ Did not know/answer

A15. Do mental health providers and services pay attention to the needs of people with disabilities?

- ☐ Yes ☐ No

A15 (b). Why do you think so?

A16. Did you want any mental health service that you could not get?

- ☐ Yes ☐ No

A16 (b). If yes, what was it?

A17. What advice would you give to mental health providers?

Section B: Interviewer Observations

Interviewer Instructions:

*Answer these questions yourself immediately after completing the survey. **Do not** discuss them with the respondent.*

B1. During the interview, the respondent seemed:

☐ Very interested ☐ Somewhat interested ☐ Indifferent ☐ Somewhat bored ☐ Very bored

B2. How forthcoming did the respondent seem?

☐ Completely forthcoming ☐ Mainly forthcoming ☐ About half and half ☐ Not forthcoming/evasive

B3. Was the interview conducted:

☐ In total privacy ☐ With someone else present

B4. Did the respondent have difficulty understanding any questions?

☐ Yes ☐ No

B4 (b). If yes, please list the question number(s)

B5. I certify that I administered this interview with the designated respondent, that I followed all question specifications, and that I will keep all information obtained during the interview confidential.

☐ Yes ☐ No

Mental health providers over the past year:

Mental health services over the past year:

Things that happened this past year:

Yes		All that I want or need
		Some, but not as much as I want or need
		Very little
No		Not at all

MENTAL HEALTH PROVIDERS

&

MENTAL HEALTH SERVICES



Prescriber

Examples: Primary Care Doctor,
Nurse, Physician Assistant, or
Psychiatrist

- Prescribes the medication you need
- Checks to see if your medication is helpful



Therapist or Counselor

Examples: Mental Health
Counselor

- Meets with you alone, with a group, or with your family
- Talks to you about your thoughts and feelings
- Helps you learn and practice coping skills like deep breathing



Crisis Response Teams

Examples: Mobile Crisis Teams,
Emergency Room, or someone at
your doctor's or therapist's office

- A crisis is when you are very upset and need help right away
- Helps you when you have a mental health crisis
- Helps you get help right away

PEIS Appendix D: PEIS Questions & Examples

PEIS Questions	Examples
1. How much do you meet with, talk to, or message with your mental health provider?	Examples: You may meet in person, on the phone, or your computer or tablet. You may also send messages in chat, text, email, or an electric medical chart.
2. How often did your mental health providers help you with something you were worried about?	Examples: Something that is bothering you, something you needed to talk about, something that was on your mind
3. How often did you get to say what you want or need for your mental health services?	Examples: Mental health providers gave you a chance to say what you want or need about: medication for your mental health; getting individual or group therapy.
4. How often did mental health services change to meet your needs?	Examples: Providing appointments at a different time, trying something that might work better for you, changing a medication if you don't like the side effects, or it did not help you.
5. How often did mental health providers ask you how much you like your mental health services?	Examples: Asking you how it's working or how it's going, if you are satisfied with how its going.
6. How often did you get the choose the person who provides your mental health services?	Examples: Mental health providers gave you a chance to: choose the therapist you want; choose the prescriber you want. <i>(Refer the respondent to the Mental Health Providers & Services Infographic)</i>
7. How often did mental health providers give you a chance to make decisions about your treatment?	Examples: Giving you choices about your medication, therapy, how often you see them, where you see them.
8. How often were you satisfied with your family member's involvement in your treatment? <i>If you don't have a family member involved, you can think about a friend or other support person who is involved in your treatment.</i>	Examples: coming to meetings or appointments when you want them to, sharing what you want them to share, helping you practice or use what you learn in therapy.
9a. How often were mental health services provided at a time and a place that was easy to get to?	Examples: Appointments that are not during your work time, the office is near to your house, a bus goes to the office.
9b. What made it hard to get services: a) services were too far away b) hard time getting transportation to services c) could not get an appointment at a time that worked with my schedule.	

10. How often did you get all the mental health services you needed?	Examples: The right services at the right time. This includes medication, therapy/counseling, and/or crisis response. Was what was offered what you needed? <i>(Refer the respondent to the Mental Health Providers & Services Infographic)</i>
11. If you had a mental health crisis, how much information did providers give you about how to feel better?	Examples: Who do you call (friend, family); What can you do (mindfulness, exercise, breathing exercise, take a walk ,journaling, listening to music, be with pets); Using your crisis plan in a way that works for you.
12. If you had a mental health crisis, how much information did you get about who to call?	Examples: Do you have a crisis plan with numbers to call/people who can help you? This might be family and friends, hotlines or warm lines, on call providers, crisis response teams.
13. If you have a mental health crisis, how much help can you get on nights or weekends?	Examples: Are there people to call or a place to go. Also think about how much help you can get on holidays.
14. How often were you satisfied with your mental health services?	Examples: Feel ok about: the medicine you take, the therapy or counseling you get, with the crisis response. <i>(Refer the respondent to the Mental Health Providers & Services Infographic)</i>
15. Do mental health providers and services pay attention to the needs of people with disabilities? 15 (b). Why do you say that?	(no standardized examples)
16. Did you want any service that you could not get? 16 (b). What was it?	(no standardized examples)
17. What advice would you give to mental health providers?	(no standardized examples)

PEIS Appendix E: Alignment of PEIS Questions with FEIS Questions

PEIS Item	FEIS Item
1. How much do you meet with, talk to, or message with your mental health provider?	B9. During the past year, how much contact did you have with any mental health professional on any matter pertaining to your family member's care?
2. How often did your mental health providers help you with something you were worried about?	B5. During the past year, how much did mental health professionals respond to your concerns about your family member?
3. How often did you get to say what you want or need for your mental health services?	B18. During the past year, how much say did you have in the outpatient mental health services that your family member received?
4. How often did mental health services change to meet your needs?	B15. During the past year, how flexible have services been to meet the needs of you and your family member?
5. How often did mental health providers ask you how much you like your mental health services?	B11. During the past year, how much opportunity was there for you to express your opinion to mental health providers about the treatment your family member received?
6. How often did you get to choose the person who provides your mental health services?	B13. During the past year, how much opportunity did you or your family member have to choose a particular case manager or therapist?
7. How often did mental health providers give you a chance to make decisions about your treatment?	B6. During the past year, how much did mental health professionals take into account your ideas and opinions about your family member's treatment?
8. How often were you satisfied with your family member's involvement in your treatment?	B19. During the past year, how much satisfaction did you feel about your role in your family member's treatment?
9a. How often were mental health services provided at a time and a place that was easy to get to?	B14. During the past year, how often were the mental health services for your family member easy to access?

9b. What made it hard to get services: a) services were too far away b) hard time getting transportation to services c) could not get an appointment at a time that worked with my schedule.	
10. How often did you get (all) the mental health services you needed?	B10. During the past year, were the available mental health services for your family member the ones you thought were needed?
11. If you had a mental health crisis, how much information did providers give you about how to feel better?	B2. During the past year, how much assistance did you get from mental health professionals regarding what to do if there were to be a crisis involving your family member?
12. If you had a mental health crisis, how much information did you get about who to call?	B3. During the past year, how much information did you get from mental health professionals regarding whom to call if there were to be a crisis involving your family member?
13. If you have a mental health crisis, how much help can you get on nights or weekends?	B20. During the past year, how much help was available to you at night or on weekends if your family member had a crisis?
14. How often were you satisfied with your mental health services?	B16. During the past year, in general, how much satisfaction did you feel about outpatient mental services your family member received?
15. Do mental health providers and services pay attention to the needs of people with disabilities? 15 (b). Why do you say that?	B17. During the past year, how much did you feel that the mental health system was responding to the wishes of family members like yourself?
16. Did you want any service that you could not get? 16 (b). What was it?	B22. During the past year, was there any particular service that your family member needed that was not available?
17. What advice would you give to mental health providers?	B23. What advice would you give to mental health providers?

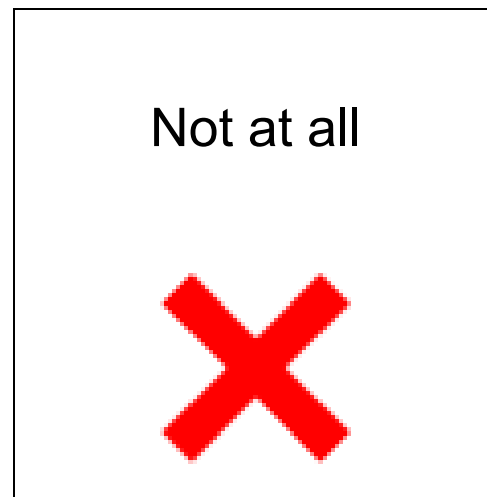
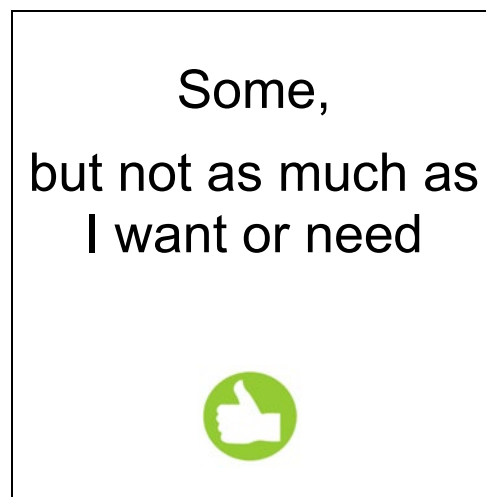
PEIS Version 1.0 Appendix F: Strategies to address mental health service experiences

PEIS Questions	Example Strategies
Input (Questions 1-5) and Choice (Questions 6-8) - These questions are aligned with the concept of accountability	▪ In addition to obtaining the individual's perspective about their treatment choices, it is important to learn about their preferences for the amount and type of support they receive when engaging with the mental health service system. ▪ Talk to family members about barriers that may be affecting their involvement in treatment and determine if additional resources or supports may be beneficial. ▪ Support the individual to identify their preferences about their services and treatment, and role-play speaking with their provider. ▪ Work with the mental health provider or the mental health team to determine an accessible way solicit their input in individual sessions (written script, pictures) or group team meetings (i.e., joining at the beginning/end of the meeting and writing a list of what they would like to share with their team). ▪ Provide family members, natural supports, and providers with information about the importance of incorporating the perspectives of people with IDD in treatment ▪ Identify a trusted support person who can attend appointments to help the individual advocate for themselves. ▪ Support individuals who desire more autonomy from their family to identify the aspects of their treatment for which they desire more independence.
Access (Questions 9-10)	▪ Share resources for transportation and assisting with linkages to services that better meet the individual's needs can help address access-related barriers. ▪ Explore options for providers that offer services through various modalities (e.g., telehealth) or appointment times that align with the individual's preferences. ▪ Educate providers about the barriers to accessing services and potential ways to better meet the individual's needs can help build systemic capacity.
Crisis (Questions 11-13) - These questions are aligned with the concept of appropriate	▪ Collaborate with the system of support to develop a crisis plan that includes information on how to get help on nights and weekends. ▪ Educate others on crisis plan implementation. ▪ Educate providers on the importance of sharing information about crisis prevention and coping strategies
General (Question 14-17) - Overall satisfaction with mental health services and providers, as well as gaps in service needs.	▪ Mental health providers may benefit from education on the individual's diagnoses, challenges, and how to best support them. Providing training on how to best support the individual and reframing negative information in a positive, strengths-based manner can help providers feel better equipped to support the individual in using their services. ▪ Assist with linkages to appropriate providers and services.

PEIS Appendix G: PEIS Response Choice Cards

The PEIS was developed as part of the research study “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities” funded by the Patient Centered Outcome Research Institute (Grant #14MN50).

Instructions: Cut out each square below and laminate for use during the PEIS administration



Person Experiences Interview Survey (PEIS) Version 1.7 (01/21/26)

The PEIS was developed as part of the research study “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities” funded by the Patient Centered Outcome Research Institute (Grant #14MN50).

Appendices (Spanish)

Appendix A: PEIS Administrator Form (Survey) v1.4

Appendix B: PEIS Administration Support Worksheet v1.0

Appendix C: PEIS Mental Health Providers & Services Infographic v1.0

Appendix D: PEIS Questions & Examples v1.0

Appendix E: Alignment of PEIS Questions with FEIS Questions v1.0

Appendix F: Strategies to Address Mental Health Service Experiences v1.0

Appendix G: PEIS Response Choice Cards v1.0

A: Encuesta de Entrevista de Experiencias Personales (PEIS) Spanish translation of English PEIS Versión 1.4 (06/10/24)

ID del respondiente			
Fecha de la Entrevista		Duración de la entrevista:	
Nombre del Entrevistador			

La PEIS en inglés significa Encuesta de Entrevista de Experiencias Personales.

PEIS se desarrolló como parte del estudio de investigación "Evaluación de los servicios de telesalud en los resultados de salud mental para personas con discapacidad intelectual y del desarrollo", financiado por el Instituto de Investigación de Resultados Centrados en el Paciente (Subvención nº 14MN50).

El PEIS y este formulario solo deben utilizarse con permiso de los autores del PEIS. Para más información, póngase en contacto con: Joan B. Beasley, PhD joan.beasley@unh.edu & Jessica M. Kramer, PhD Jessica.kramer@phhp.ufl.edu

Instrucciones para el entrevistador:

Recuerde al respondiente que el objetivo de administrar el PEIS es conocer mejor sus experiencias con el sistema de servicios de la salud mental. La información se utilizará para mejorar los servicios de la salud mental. Asegure al respondiente que la información que proporcione será confidencial y que no existen respuestas correctas o incorrectas.

Cuando se administre, es necesario utilizar el "Apéndice B Hoja de trabajo de apoyo a la administración del PEIS" y el "Apéndice C: Infografía sobre proveedores y servicios de la salud mental del PEIS".

[El vídeo de introducción al PEIS](#) enseña a los respondiente a completar el PEIS

Alguien brindó apoyo durante la entrevista PEIS (excluidos los proveedores de START):

- ☐ Ninguna ☐ Padres/Padrastró ☐ Pariente (otro) ☐ Empleado personal
- ☐ Encargado del caso/Coordinador de servicios
- ☐ Otro: _____

"Introduction to the PEIS" video (Spanish)



Sección A: Evaluación Personal de los Servicios de Salud Mental

Instrucciones para el entrevistador: Lea cada pregunta tal como está escrita y utilice la " Apéndice B: Hoja de trabajo de apoyo a la administración del PEIS" y la " Apéndice C: AppenInfografía sobre proveedores y servicios de la salud mental del PEIS" durante la administración.

Ayude a los encuestados a responder a cada pregunta 1) animándoles a pensar en voz alta mientras eligen su respuesta, 2) proporcionándoles ejemplos (véase el "Apéndice D: Preguntas y ejemplos del PEIS"), y 3) utilizando el nombre de su(s) servicio(s) o proveedor(es) de salud mental específico(s) en la pregunta. Todas las preguntas se refieren a experiencias con servicios y proveedores de la salud mental durante el pasado año (12 meses).

En el pasado año

Nada [1]	Muy poca [2]	Algo, pero no tanto como lo que quiero o necesito [3]	Todo lo que quiero o necesito [4]
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Práctica: Piensa en una actividad que te gusta hacer. ¿Cuánto hiciste esa actividad durante el pasado año?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A1. ¿Con qué frecuencia te reúnes, hablas o te mensajeas con tu proveedor de la salud mental?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A2. ¿Con qué frecuencia sus proveedores de la salud mental le ayudaron con algo que le preocupaba?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A3. ¿Con qué frecuencia tuvo la oportunidad de decir lo que quería o necesitaba para tus servicios de la salud mental?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A4. ¿Con qué frecuencia cambiaron los servicios de la salud mental para satisfacer a tus necesidades?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A5. ¿Con qué frecuencia los proveedores de los servicios de la salud mental te preguntaron cuanto te gustaban los servicios?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A6. ¿Con qué frecuencia tuvo la oportunidad elegir a la persona que brindaba servicios de la salud mental?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A7. ¿Con qué frecuencia los proveedores de la salud mental le dieron la oportunidad de tomar decisiones sobre tu tratamiento?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A8. ¿Con qué frecuencia estaba satisfecho/a con la participación de su familiar en su tratamiento? *Si no tiene un familiar que participe, puede pensar en un amigo u otra persona de apoyo que participa en su tratamiento.*

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A9. ¿Con qué frecuencia se brindaron servicios de la salud mental en un tiempo y lugar de fácil acceso?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A9 (b) ¿Qué hizo difícil obtener servicios?: (Marque todo lo que corresponda)

- ☐ (a) los servicios estaban demasiado lejos
 ☐ (b) dificultad para conseguir transporte a los servicios
 ☐ no pudo conseguir una cita a una hora que funcione con mi horario.

☐ Otra razón, por favor describa: _____

A10. ¿Con qué frecuencia recibió todos los servicios de la salud mental que necesitabas?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A11. Si tuviste una crisis de la salud mental, ¿cuánta información te dieron los proveedores sobre cómo sentirte mejor?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A12. Si tuviste una crisis de la salud mental, ¿cuánta información recibiste sobre a quién llamar?

- ☐ Nada
 ☐ Muy poca
 ☐ Algo, pero no tanto como lo que quiero o necesito
 ☐ Todo lo que quiero o necesito
 ☐ No Sabe/No responde

A13. Si tiene una crisis de la salud mental, ¿cuánta ayuda puede recibir por las noches o los fines de semana?

- ☐ Nada ☐ Muy poca ☐ Algo, pero no tanto como lo que quiero o necesito ☐ Todo lo que quiero o necesito ☐ No Sabe/No responde

A14. ¿Con qué frecuencia se sintió satisfecho con sus servicios de la salud mental?

- ☐ Nada ☐ Muy poca ☐ Algo, pero no tanto como lo que quiero o necesito ☐ Todo lo que quiero o necesito ☐ No Sabe/No responde

A15. ¿Prestan atención los proveedores y servicios de la salud mental a las necesidades de las personas con discapacidades?

- ☐ Si ☐ No

A15 (b). ¿Por qué lo dice?

A16. ¿Deseaba algún servicio que no pudo obtener?

- ☐ Si ☐ No

A16 (b). ¿Qué fue?

A17. ¿Qué consejo le daría usted a los proveedores de la salud mental?

Sección B: Observaciones del entrevistador***Instrucciones para el entrevistador:***

*Responda usted mismo a estas preguntas inmediatamente después de completar la encuesta.
No las comente con el encuestado.*

B1. Durante la entrevista, el entrevistado parecía:

☐ Muy interesado ☐ Algo interesado ☐ Indiferente ☐ Algo aburrido ☐ Muy aburrido

B2. ¿Cuán comunicativo parecía el encuestado?

☐ Completamente comunicativo ☐ Principalmente comunicativo ☐ 50% y 50% ☐ No comunicativo/ evasivo

B3. La entrevista se realizó:

☐ En total privacidad ☐ Con alguien más presente

B4. ¿Tuvo el encuestado dificultades para entender alguna pregunta?

☐ Si ☐ No

B4 (b). Si la respuesta es sí, indique el/los número(s) de la(s) pregunta(s)

B5. Certifico que he llevado a cabo esta entrevista con el entrevistado designado, que he seguido todas las especificaciones de las preguntas y que mantendré confidencial toda la información obtenida durante la entrevista.

☐ Si ☐ No

**Proveedores de la salud mental
durante el año pasado:**

**Servicios de la salud mental
durante el año pasado:**

**Cosas que pasaron el año
pasado:**



Proveedores De La Salud Mental & Servicios De La Salud Mental



Recetador

Ejemplos: Médico de atención primaria, enfermero/a, asistente médico o psiquiatra

- Le receta los medicamentos que necesita
- Comprueba que el medicamento sea útil



Terapista o consejero

Ejemplos: Consejero de la salud mental

- Se reúne con usted a solas, en grupo o con su familia
- Habla con usted sobre sus pensamientos y sentimientos
- Le ayuda a aprender y practicar técnicas de afrontamiento, como la respiración profunda



Equipos de Respuesta a Crisis

Ejemplos: Equipos Móviles de Crisis, Sala de Emergencias, o alguien en la consulta de su médico o terapeuta

- Una crisis es cuando estas muy angustiado y necesitas ayuda de inmediato
- Te ayuda cuando tienes una crisis de la salud mental
- Te ayuda a obtener ayuda de inmediato

PEIS Apéndice D: Preguntas y ejemplos de la PEIS

Preguntas PEIS	Ejemplos
1. ¿Con qué frecuencia te reúnes, hablas o te mensajeas con tu proveedor de la salud mental?	Ejemplo: Puede reunirse en persona, por teléfono, o en la computadora o tableta. También puedes enviar mensajes por chat, texto, correo electrónico o un cuadro médico electrónico.
2. ¿Con qué frecuencia sus proveedores de la salud mental le ayudaron con algo que le preocupaba?	Ejemplo: Algo que te molestaba, algo de lo que necesitabas hablar, algo que estaba en tu mente.
3. ¿Con qué frecuencia tuvo la oportunidad de decir lo que quería o necesitaba para tus servicios de la salud mental?	Ejemplo: Sobre los medicamentos para su salud mental. Acerca de recibir terapia individual o de grupo.
4. ¿Con qué frecuencia cambiaron los servicios de la salud mental para satisfacer a tus necesidades?	Ejemplo: Proporcionar citas a una hora diferente, intentar algo que podría trabajar mejor para usted, cambiando un medicamento si no le gustan los efectos secundarios, o no le ayudó.
5. ¿Con qué frecuencia los proveedores de los servicios de la salud mental te preguntaron cuanto te gustaban los servicios?	Ejemplo: Preguntarle cómo funciona o cómo va. Si está satisfecha/o con cómo va.
6. ¿Con qué frecuencia tuvo la oportunidad elegir a la persona que brindaba servicios de la salud mental?	Ejemplo: Elegir el terapeuta que desea, elegir el recetador que desea. <i>(Remita al encuestado a la infografía sobre proveedores y servicios de la salud mental)</i>
7. ¿Con qué frecuencia los proveedores de la salud mental le dieron la oportunidad de tomar decisiones sobre tu tratamiento?	Ejemplo: Dándole opciones sobre su medicamento, terapia, con qué frecuencia los ve y dónde los ve.
8. ¿Con qué frecuencia estaba satisfecho/a con la participación de su familiar en su tratamiento? Si no tiene un familiar que participe, puede pensar en un amigo u otra persona de apoyo que participa en su tratamiento.	Ejemplo: Venir a reuniones o citas cuando usted lo desee, compartiendo lo que quieres que compartan, ayudarle a practicar o a utilizar lo que aprende en la terapia.
9a. ¿Con qué frecuencia se brindaron servicios de la salud mental en un tiempo y lugar de fácil acceso?	Ejemplo: Citas que no son durante su horario de trabajo, la oficina está cerca de su casa, un autobús va a la oficina.
9b. Qué hizo difícil obtener servicios: a) los servicios estaban demasiado lejos b) dificultad para conseguir transporte a los servicios c) no pudo conseguir una cita a una hora que funcione con mi horario.	

10. ¿Con qué frecuencia recibió todos los servicios de la salud mental que necesitabas?	Ejemplo: Los servicios adecuados en el momento adecuado. Esto incluye medicamentos, terapia/consejería y/o respuesta a crisis. ¿Lo que le ofrecieron era lo que necesitaba? <i>(Remita al encuestado a la Infografía sobre proveedores y servicios de la salud mental)</i>
11. Si tuviste una crisis de la salud mental, ¿cuánta información te dieron los proveedores sobre cómo sentirte mejor?	Ejemplo: A quién llamar (amigo, familiar); Qué puedes hacer (“mindfulness”- técnica de meditación, ejercicio físico, ejercicio de respiración, dar una caminata, escribir en un diario, escuchar música, estar con mascotas); Utilizar tu plan de crisis de una forma que funcione para ti.
12. Si tuviste una crisis de la salud mental, ¿cuánta información recibiste sobre a quién llamar?	Ejemplo: ¿Tienes un plan de crisis con números de teléfono y personas que pueden ayudarte? Puede tratarse de familiares y amigos, líneas directas-de ayuda, proveedores de servicios de guardia o equipos de respuesta a crisis.
13. Si tiene una crisis de la salud mental, ¿Cuánta ayuda puede recibir por las noches o los fines de semana?	Ejemplo: ¿Hay gente a la que puede llamar o un lugar al que ir? Piensa también en la ayuda que puedes recibir durante los días festivos.
14. ¿Con qué frecuencia se sintió satisfecho con sus servicios de la salud mental?	Ejemplo: Sintiéndose bien con: los medicamentos que toma, la terapia o consejería que recibe, con la respuesta a las crisis. <i>(Remita al encuestado a la infografía sobre proveedores y servicios de la salud mental)</i>
15. ¿Prestan atención los proveedores y servicios de la salud mental a las necesidades de las personas con discapacidades? 15 (b). ¿Por qué lo dice?	(sin ejemplos estandarizados)
16. ¿Deseaba algún servicio que no pudo obtener? 16 (b). ¿Qué fue?	(sin ejemplos estandarizados)
17. ¿Qué consejo le daría usted a los proveedores de la salud mental?	(sin ejemplos estandarizados)

PEIS Appendix E: Alignment of PEIS Questions with FEIS Questions

Preguntas PEIS	FEIS Item
1. ¿Con qué frecuencia te reúnes, hablas o te mensajeas con tu proveedor de la salud mental?	B9. Durante el último año, ¿cuántos contactos tuvo con un profesional de salud mental sobre algún asunto relacionado con el cuidado de su familiar?
2. ¿Con qué frecuencia sus proveedores de la salud mental le ayudaron con algo que le preocupaba?	B5. Durante el último año, ¿en qué medida los profesionales de salud mental tomaron en cuenta sus ideas y opiniones sobre el tratamiento de su familiar?
3. ¿Con qué frecuencia tuvo la oportunidad de decir lo que quería o necesitaba para tus servicios de la salud mental?	B18. Durante el último año, ¿qué papel tuvo usted en los servicios ambulatorios de salud mental que recibió su familiar?
4. ¿Con qué frecuencia cambiaron los servicios de la salud mental para satisfacer a tus necesidades?	B15. Durante el último año, ¿los servicios ofrecidos han sido lo suficientemente flexibles para satisfacer las necesidades de usted y de su familiar?
5. ¿Con qué frecuencia los proveedores de los servicios de la salud mental te preguntaron cuanto te gustaban los servicios?	B11. Durante el último año, ¿cuántas oportunidades tuvo de expresar su opinión a los profesionales de salud mental sobre el tratamiento que recibió su familiar?
6. ¿Con qué frecuencia tuvo la oportunidad elegir a la persona que brindaba servicios de la salud mental?	B13. Durante el último año, ¿cuántas oportunidades tuvieron usted o su familiar de elegir un administrador del caso o terapeuta en particular?
7. ¿Con qué frecuencia los proveedores de la salud mental le dieron la oportunidad de tomar decisiones sobre tu tratamiento?	B6. Durante el último año, ¿en qué medida los profesionales de salud mental tomaron en cuenta sus ideas y opiniones sobre el tratamiento de su familiar?
8. ¿Con qué frecuencia estaba satisfecho/a con la participación de su familiar en su tratamiento? Si no tiene un familiar que participe, puede pensar en un amigo u otra persona de apoyo que participa en su tratamiento.	B19. Durante el último año, ¿qué grado de satisfacción sintió acerca de su papel en el tratamiento de su familiar?
9a. ¿Con qué frecuencia se brindaron servicios de la salud mental en un tiempo y lugar de fácil acceso?	B14. Durante el último año, ¿con qué frecuencia fue fácil acceder a los servicios de salud mental para su familiar?

9b. Qué hizo difícil obtener servicios: a) los servicios estaban demasiado lejos b) dificultad para conseguir transporte a los servicios c) no pudo conseguir una cita a una hora que funcione con mi horario.	B14b. Durante el último año, si no fue fácil acceder a los servicios, ¿cuáles fueron las principales barreras? (Marque todas las opciones que correspondan) a) Servicios demasiado lejos b) Problemas de transporte c) Horas incómodas d) Otra, describa: _____
10. ¿Con qué frecuencia recibió todos los servicios de la salud mental que necesitabas?	B10. Durante el último año, ¿los servicios de salud mental disponibles para su familiar eran los que usted consideraba necesarios?
11. Si tuviste una crisis de la salud mental, ¿cuánta información te dieron los proveedores sobre cómo sentirte mejor?	B2. Durante el último año, ¿cuánta asistencia recibió de los profesionales de salud mental con respecto a lo que debe hacer si hubiese una crisis con su familiar?
12. Si tuviste una crisis de la salud mental, ¿cuánta información recibiste sobre a quién llamar?	B3. Durante el último año, ¿cuánta información recibió de los profesionales de salud mental con respecto a quién llamar si hubiese una crisis con su familiar?
13. Si tiene una crisis de la salud mental, ¿Cuánta ayuda puede recibir por las noches o los fines de semana?	B20. Durante el último año, ¿cuánta ayuda tuvo a su disposición por la noche o los fines de semana si su familiar tuvo una crisis?
14. ¿Con qué frecuencia se sintió satisfecho con sus servicios de la salud mental?	B16. Durante el último año, en general, ¿qué grado de satisfacción sintió acerca de los servicios ambulatorios de salud mental que recibió su familiar?
15. ¿Prestan atención los proveedores y servicios de la salud mental a las necesidades de las personas con discapacidades? 15 (b). ¿Por qué lo dice?	B17. Durante el último año, ¿en qué medida sintió que el sistema de salud mental respondía a los deseos de familiares como usted?
16. ¿Deseaba algún servicio que no pudo obtener? 16 (b). ¿Qué fue?	B22. Durante el último año, ¿hubo algún servicio en particular que su familiar necesitara y que no estuviera disponible?
17. ¿Qué consejo le daría usted a los proveedores de la salud mental?	B23. ¿Qué consejo daría a los planificadores de servicios en relación con las necesidades de servicios de salud mental de las personas con IDD y sus familias?

PEIS Version 1.0 Appendix F: Strategies to address mental health service experiences

PEIS Questions	Example Strategies
Input (Questions 1-5) and Choice (Questions 6-8) - These questions are aligned with the concept of accountability	▪ In addition to obtaining the individual's perspective about their treatment choices, it is important to learn about their preferences for the amount and type of support they receive when engaging with the mental health service system. ▪ Talk to family members about barriers that may be affecting their involvement in treatment and determine if additional resources or supports may be beneficial. ▪ Support the individual to identify their preferences about their services and treatment, and role-play speaking with their provider. ▪ Work with the mental health provider or the mental health team to determine an accessible way solicit their input in individual sessions (written script, pictures) or group team meetings (i.e., joining at the beginning/end of the meeting and writing a list of what they would like to share with their team). ▪ Provide family members, natural supports, and providers with information about the importance of incorporating the perspectives of people with IDD in treatment ▪ Identify a trusted support person who can attend appointments to help the individual advocate for themselves. ▪ Support individuals who desire more autonomy from their family to identify the aspects of their treatment for which they desire more independence.
Access (Questions 9-10)	▪ Share resources for transportation and assisting with linkages to services that better meet the individual's needs can help address access-related barriers. ▪ Explore options for providers that offer services through various modalities (e.g., telehealth) or appointment times that align with the individual's preferences. ▪ Educate providers about the barriers to accessing services and potential ways to better meet the individual's needs can help build systemic capacity.
Crisis (Questions 11-13) - These questions are aligned with the concept of appropriate	▪ Collaborate with the system of support to develop a crisis plan that includes information on how to get help on nights and weekends. ▪ Educate others on crisis plan implementation. ▪ Educate providers on the importance of sharing information about crisis prevention and coping strategies
General (Question 14-17) - Overall satisfaction with mental health services and providers, as well as gaps in service needs.	▪ Mental health providers may benefit from education on the individual's diagnoses, challenges, and how to best support them. Providing training on how to best support the individual and reframing negative information in a positive, strengths-based manner can help providers feel better equipped to support the individual in using their services. ▪ Assist with linkages to appropriate providers and services.

PEIS Appendix G: PEIS Response Choice Cards

The PEIS was developed as part of the research study “Evaluation of Telehealth Services on Mental Health Outcomes for People with Intellectual and Developmental Disabilities” funded by the Patient Centered Outcome Research Institute (Grant #14MN50).

Instructions: Cut out each square below and laminate for use during the PEIS administration

