INDIANA

INDIVIDUAL EXPERIENCE SURVEY

DEFINITIONS AND INSTRUCTIONS

Thank you for completing the Individual Experience Survey (IES) data collection form. The Individual Experience Survey (IES) is a web-based information management application funded by the Division of Disability and Rehabilitative Services (DDRS), specifically the Bureau of Developmental Disabilities Services (BDDS). If you have any questions regarding this instructional booklet, data entry or system, please contact the Center on Community Living and Careers at the Indiana Institute on Disability and Community, Indiana University at cclc@indiana.eduor (812) 855-6508.

For programmatic questions or specific client questions please contact the BDDS CMCO Liaison at <u>Beckie.Minglin1@fssa.IN.gov</u>

The system is designed to:

- 1. Provide better information about the choices, experiences and outcomes achieved by individuals receiving M dicaid waiver services. For example, the system includes measures related to where the individual spends time and how integrated they are in the community.
- 2. Data entry will occur from July –December with data analysis starting in January. That is, the data that is reported to the state is the data that will be downloaded as of December 31. Data will be gathered during quarterly or annual meetings with clients and others.
- 3. Collect data on an individual service recipient basis, rather than at a program level.
- 4. Conduct occasional "special studies" in which we would ask a small set of questions on a targeted topic (e.g., more in-depth information on roommate selection).
- 5. Document statewide and regional outcomes
- 6. Provide information for State policy makers, State and local decision-making and legislators.



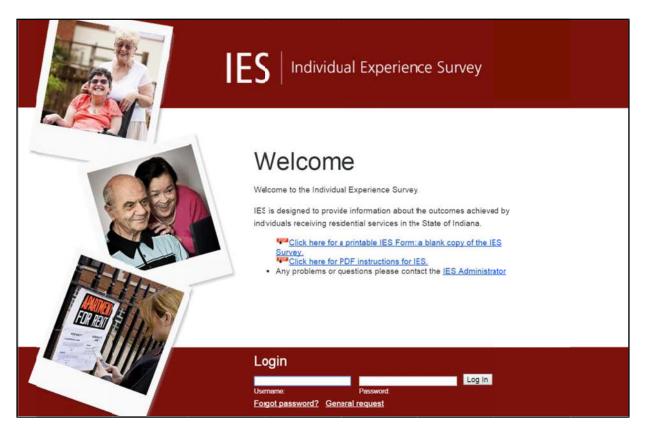
COMPUTER TECHNICAL INFORMATION

Browser Requirements and Settings

This IES interface is compatible with all major browsers (ex. Internet Explorer, Firefox, Chrome, Opera)

Date Entry Information

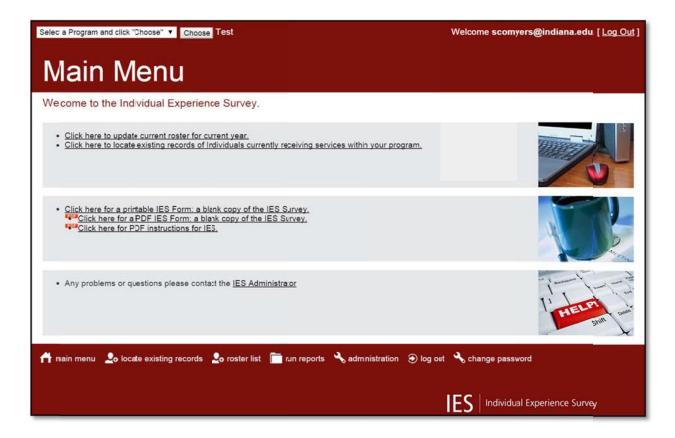
1. Website: https://ios.webhost.iu.edu



2. <u>Password Information</u> – Each individual will be given a "username" and "password" so each individual user can only access their agency's databases. The username will be an active email account to which the user currently has access. The system will generate a temporary password and will prompt you to change it on your first login.



- 3. <u>Logging On Difficulties</u> On the IES Login page in the middle of the screen you will see a link to request a forgotten username or password. Click on the link to be taken to a form allowing for automatic password reset. You will be automatically emailed a temporary password which you can change upon entering the site for the first time. REMEMBER your username is your email account. If you have any other concerns, contact the Center on Community Living and Careers at the Indiana Institute on Disability and Community, Indiana University at <u>cclc@indiana.edu</u>or (812) 855-6508.
- 4. Finding and/or Adding List of Participants. To add a participant and/or find your list of participants
 - Go to "Main Menu" page
 - You can either -Click on the link "Click here to update current roster for current year" or
 - Use tabs at bottom of page to "add new records", "locate existing records" or "oster list"



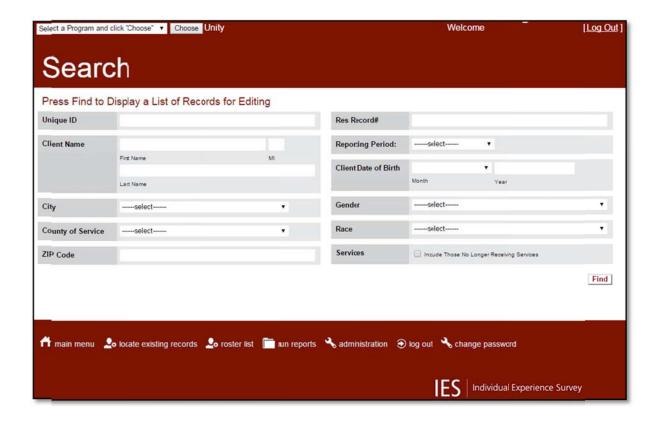
5. Updating an Existing Record.

To update any of the existing data in the individual's record (e.g., change in living environment) that has changed within the reporting period:

Go to "Main Menu" page



- Click on the link "Click here to locate existing records of individuals currently receiving services in your program" or use tabs at bottom of page
- On the Search/Edit form there are 11 fields which can be used to apply search criteria. Enter enough information to find the entry of interest (i.e., last name, reporting period, etc.). Click on the "Find" button in the lower right side of the display and the "Search Results" will be displayed in a table.
- Click on the entry of interest and the IOS form will be displayed allowing the user to make any changes necessary. Save the changes by clicking on the "Submit" button.
- When prompted "Are you sure you want to update this entry"? Choose "yes" if you wish and a dialog box will be displayed informing you that the update was successful.



6. <u>Additional Questions</u> - For general questions, contact the Center on Community Living and Careers, Indiana Institute on Disability and Community, Indiana University, at (812) 855-6508 or cclc@indiana.edu.

DATA ENTRY FORM DEFINITIONS AND INSTRUCTIONS

Case managers will submit the Individual Experience Survey (IES) data for individuals receiving Medicaid services as required by DDRS to the Center on Community Living and Careers. The Center will summarize this information to complete a "snap shot" of the outcomes reported which results in a report depicting the aggregate averages. The information will be required to be entered—July through December.

I. Demographic Information

The majority of all demographic information will be pre-populated except for the following -

Race

Click on the box to select the individual's race.

Primary Disability

Select the disability that *most* impacts or impedes the individual's daily life activities.

- Physical includes such areas as spina bifida, spinal cord injury, polio, etc.
- Other Health Impairments includes such areas as diabetes, asthma, cystic fibrosis, etc.

Secondary Disability

If the individual has more than one identified disability (e.g., intellectual disability and mental illness, intellectual disability and cerebral palsy), select the disability that was not identified in the primary but also impacts or impedes their daily life activities.

If the individual *does not* have a secondary disability, select *none*.

Mobility

Select the mode of mobility primarily used by the individual. "Ambulatory with assistance" relates to individuals who may be ambulatory but need some assistance such as holding onto someone's arm or a wall for support.



Behavioral Issues

If the individual exhibits behaviors that interfere with his or her daily activities, job or may need assistance in attaining more appropriate expressions of emotions or desires, select the level of intensity of the behaviors displayed.

Level of Support for Behaviors

Select the level of support needed by the individual where

- Continuous requires constant supervision and support
- <u>Intermittent</u> does not require constant supervision of support however the individual requires a fairly regular schedule (e.g., once a week) of supervision and support
- Occasional requires the support or supervision only occasionally and usually because of an event or change of event (e.g., change of medication, change to a new apartment)
- N/A Not applicable (checked "none" under behavior issues above)

Communication

Select the mode of communication primarily used by the individual. Check only one.

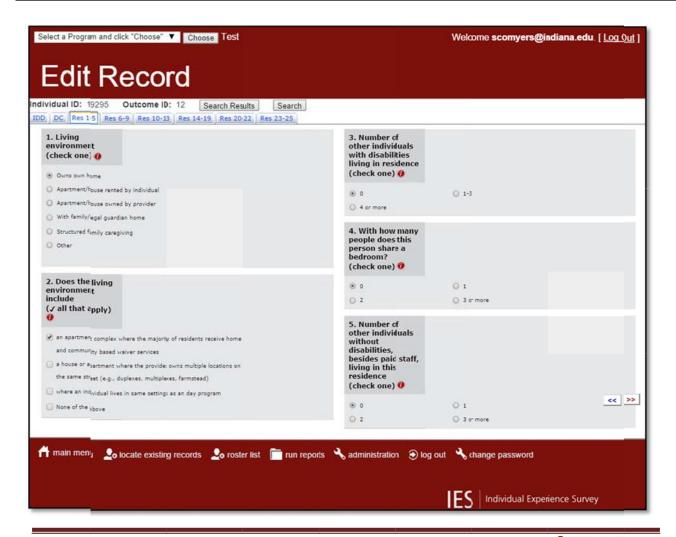
Level of Personal Assistance

Select all areas of personal assistance required by the individual. If the individual does not need any assistance, check not applicable –NA.



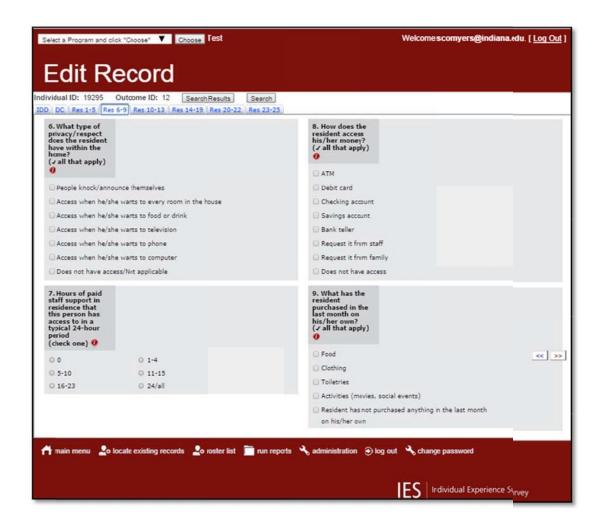
II. Information Related to Experiences

For each of the 25 questions, you will see a screen shot of the question. Following the screen shot of the question are instructions and/or suggestions for getting accurate informa ion from the consumer or those involved in the interview. We also offer you a "script" to help you introduce the survey and some of the questions.



Questions		alking Points
1.	Living Environment - Owns own home - Apartment/house rented by individual - Apartment/house owned by provider - With family/legal guardian home - Structured family caregiving - Other:	 Select the individual's living environment. (This question may need to be answered by the service provider, if not already known) Can you tell me where you live? Is it a house? An apartment? If you rent it and from whom? If answered "Apartment/house owned by provider" then go to question 2; if not, respond "none of the above" to question 2.
2.	 Does the living environment in lude: an apartment complex where the majority of residents receive home and community based waiver services. a house or apartment where the provider owns multiple locations on the same street (e.g., duplexes, multiplexes, farmstead) where an individual lives in same settings as a day program None of the above 	This question may need to be answered by the service provider, if not already known)
3.	Number of other individuals with disabilities living in residence? - 0 - 1-3 - 4 or more	 How many house mates (with disabilities) do you have? This question may need to be answered by the service provider, if not already known). If individual is on CIH, may be easy to determine If only on FSW, may only be with family, however may still have other folks with disabilities (if known)
4.	With how many people does this person share a bedroom? - 0 - 1 - 2 - 3 or more	Do you have your own bedroom or do you share a bedroom?
5.	Number of individuals without disabilities, besides paid staff, living in this residence? - 0 - 1 - 2 - 3 or more	 This question will depend on the living environment (e.g., family residence vs own place). How many people without disabilities live with you? This question may need to be answered by the service provider, if not already known)





Questions

What type of privacy/respect does the resident have within the home? (check all that apply)

- People knock/announce themselves
- Access when he/she wants to every room in the house
- Access when he/she wants to food or drink
- Access when he/she wants to television
- Access when he/she wants to phone
- Access when he/she wants to computer
- Does not have access/Not applicable

NOTE: this question refers to if an individual can access/use when they want it vs based on a housemate's schedule, home schedule, or a housemate behavior dominating the access.

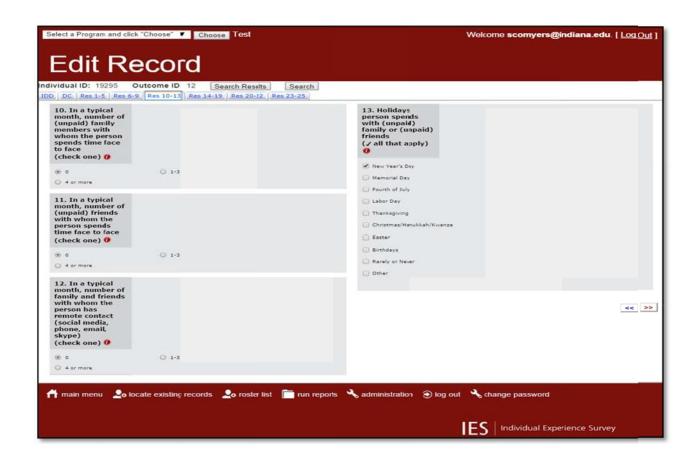
alking Points

- I'm going to ask you some questions about privacy in your home and being treated respectfully. We know that there are times when you have to share items or wait your turn for things, but in general we want to know if you can have these things when you want them.
 - When someone, (like staff, mom/dad, siblings, other housemates) comes into your room or house, do they knock and tell you who they are?
 - What do you do if you want to go to the kitchen, or living room or bedroom, such as, to get some water or to watch TV, do you just go or are you only allowed to be there during certain times?
 - What do you do when you want something to eat or drink? Do you just go to the kitchen and get something or do you have to ask a staff



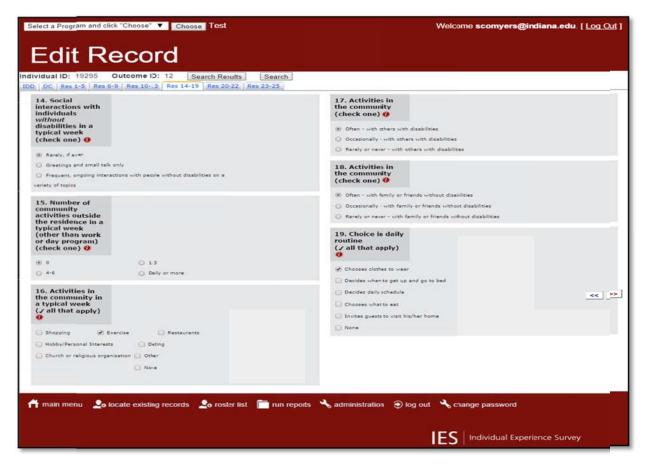
	 member? What do you do when you want to watch TV? (If a person has their own TV in their room, then they would have access) What do you do when you want to use the phone? Do you have a computer? Do you use it when you want to play games, write emails, get on and just look at things?
 7. Hours of paid staff support in residence that this person has access to in a typical 24-hour period? 0 1-4 5 - 10 11-15 16-23 24/all 	This question may need to be answered by the service provider, if not already known)
8. How does the resident access his/her money? (check all that apply) ATM Debit Card Checking account Savings account Bank teller Request it from staff Request it from family Does not have access	If you need money to go out (to the movies, restaurant or whatever you like to do), tell me how do you get your money? (may need to probe about where it is kept or who keeps it, etc.).
 9. What has the resident purchased in the last month on his/her own (check all that apply)? Food Clothing Toiletries Activities (movies, social events) Resident has not purchased anything in the las month on his/her own 	 What have you bought lately, like in the last month on your own (i.e., even with supports if needed and no one bought it for them). Did you buy any ? (look at list) For many individuals, they will need assistance in purchasing the item due to difficulty with money skills, however this is about choice and partial participation.





Questions	Talking Points
10. In a typical month, number of (unpaid) family memb rs with whom the person spends time face to face? - 0 - 1-3 - 4 or more	 Do you ever see your family (don't ask question if you know for sure they do not or if it is a sensitive issue)? How often do you go see your family?
11. In a typical month, number of (unpaid) friends with whom the person spends time face to face? - 0 - 1-3 - 4 or more	 Do you ever go out with your friends? How often do you go do things and see your friends (you may need to ask who they are and how they know them to determine if they are paid or unpaid?
12. In a typical month, number of family and friends with whom the person has remote contact (social media, phone, email, skype)? - 0 - 1-3 - 4 or more	If you don't see your family or friends face-to-face, do you ever talk to them on the phone, email, skype, or face-time? How often?
13. Holidays person spends with (unpaid) family or (unpaid) friends? (check all that apply) - New Years - Memorial Day - Fourth of July - Labor Day - Thanksgiving - Christmas/Hanukkah/Kwanza - Easter - Birthdays - Rarely or Never - Other:	Do you ever spend holidays (give a few examples) with your family and friends? Which ones? (This question may need to be answered by the service provider, if not already known).



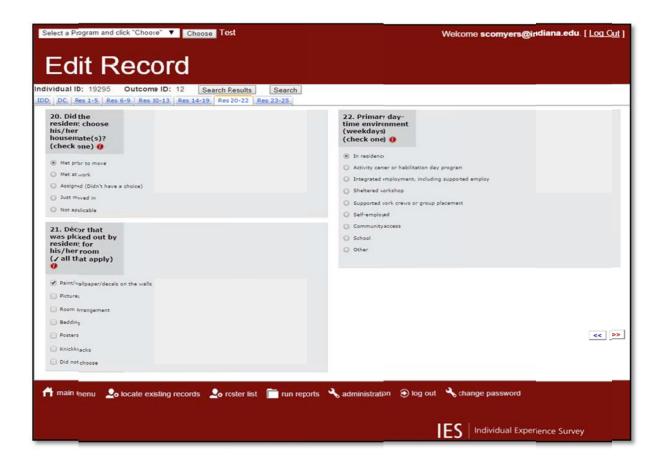


Questions 14. Social interactions with individuals without disabilities in a typical week - Rarely, if ever - Greetings and small talk only - Frequent, ongoing interactions with people without disabilities on a variety of topics	Talking Points How often does the individual interact with people without disabilities (initiate conversation, respond to interactions). This question may need to be answered by the service provider, if not already known.
 15. Number of community activities outside the residence in a typical week? (other than work or day program 0 1-3 4-6 Daily or more 	How often during the week do you go do other things than work or the day program (e.g., go to the park, go to a movie, out to eat, see friends)?
16. Activities in the community in a typical week? (check all that apply) - Shopping - Restaurants - Hobby/Personal Interests - Exercise - Dating - Church or religious organization - Other: - None	When you go out of your home and not to work or the day program during a week, where do you usually go or what do you do? Might ask specific questions such as do you go shopping every week?

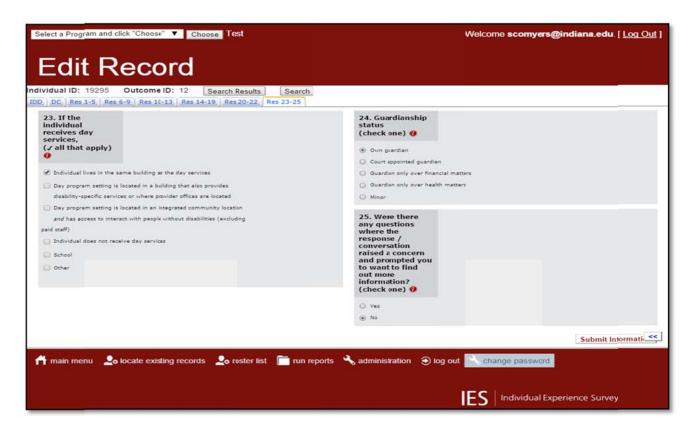


Questions 17. Activities in the community? - Often- with others with disabilities - Occasionally – with other with disabilities - Rarely or never-others with disabilities	Talking Points Who do you go with to do things in the community or activities? (you may have to ask more probing question to determine if they are people with or without disabilities such as do they work with you, how do you know them, are they staff here etc.).
Activities in the community? Often- with others without disabilities Occasionally – with other without disabilities Rarely or never-others without disabilities	Who do you go with to do things in the community or activities? (you may have to ask more probing question to determine if they are people with or without disabilities, such as - do they work with you, how do you know them, are they staff here etc.).
19. Choice in daily routines? (check all that apply) - Chooses clothes to wear - Decides when to get up and go to bed - Decides daily schedule - Chooses what to eat - Invites guess to visit his/her home - None	 I'm going to ask you some questions about the choices you make daily? I want to know more about your schedules and routines. Do you choose your clothes (may need to probe and ask when do you decide what to wear) Do you decide when to get up and go to bed? (A person needs to get up and go to work, is different than everyone gets up at 6:00 AM). Do you decide what you want to do, like on Saturdays and Sundays? How do you decide what you want to do every day? Do you decide what to do? How do you choose what to eat? Do you decide what to eat? Do you ever invite people to your home? Do you get to decide that?





20. Did the resident choose his/her housemate(s)? - Met prior to move - Met at work - Assigned (Didn't have a choice) - Just moved in - No applicable	 If the person is living with other housemates, how did you and your housemates (and if you know his/her names) decide to live together? If you need to probe, ask did you meet (go through list on left side of column)
21. Décor that was picked out by resident for his/her room? (check all that apply) - Paint/wallpaper/decals on the walls - Pictures - Room arrangement - Bedding - Posters - Knickknacks - Did not choose	 When you moved in, tell me about who decorated your bedroom for you? Did you decide on: What is on your walls? Where you were going to put your bed and dresser? Your bedspread/comforter Any posters? Little statues, pictures, or figurines
22. Primary day-time environment (weekdays) - In residence - Activity center or habilitation day program - Integrated employment, including supported employment - Sheltered workshop - Supported work crews or group placement - Self-employed - Community access - School - Other	This question may need to be answered by the service provider, if not already known or unless you are meeting at the day-time environment.



23. If the individual receives day services, (check If individual receives day services, then determine all that apply) where it is located? (This question may need to be Individual lives in the same building as the answered by the service provider, if not already day services known or unless you are meeting at the day-time Day program setting is located in a building environment). that also provides disability-specific services or where provider offices are located Day program setting is located in an integrated community location and has access to interact with people without disabilities (excluding paid staff) Individual does not receive day services School Other 24. Guardianship status If individual does not know, this question may Own guardian need to be answered by the service provider, if Court appointed guardian not already known. Guardian only over financial matters Guardian only over health matters Minor 25. Were t ere any questions where the This question is for you as a CM to determine if response/conversation raised a concern and you want to do further exploration into a situation. prompted you to want to find out more The numbers will only be aggregated. information?

SUBMIT INFORMATION! CONTINUE DATA ENTRY OR LOG OUT BY SELECTING LOG OUT BUTTON ON THE BOTTOM NAVIGATION BAR MENU THANK YOU FOR YOUR TIME AND EFFORT!!!

