

APPENDIX

B

SUSTAINABILITY PLANNING PROJECT

SURVEY QUESTIONS

**A Roadmap for Future
Planning for Adults with
Disabilities and the Families,
Providers and Administrators
that Support Them**



One component of the Sustainability Planning Project was to conduct a community survey to better understand current levels of transition planning, identify needs, challenges and barriers for later years transition, and prioritize opportunities for successful transition planning. The survey included a mix of quantitative (multiple choice, ranking) and qualitative (open answer) methods. The survey design was informed by DiClemente & Prochaska's Stages of Change behavioral model as well as recent sustainability planning surveys fielded by researchers at the University of Minnesota and participant directed advocates of Georgia. The survey was administered in English and Spanish. Waiver participants, their natural caregivers, other family members, and support brokers were invited to take the survey. The survey included the following 42 questions.

General Questions: In this part of the survey, we ask a few general questions about your role and status as it relates to later years transition planning, when the natural caregiver(s) is no longer able to provide support.

1. What is your role as it relates to the person with I/DD?
2. Does the person with I/DD receive DDA Waiver Services?
3. Does the person with I/DD self-direct their DDA Waiver Services?
4. To what extent has there been later years transition planning for the person with I/DD?

Transition Experience: The next set of questions are for people who have transitioned.

5. How old was the person with I/DD when later years transition planning began for a replacement of the natural caregiver?
6. How old was the natural caregiver(s) when later years transition planning began? (*move the circle*)
7. Please provide your primary reasons for transitioning the natural caregiver replacement
8. Think about the time **BEFORE** the later years transition. What was ONE thing that concerned you the most about the future?
9. Think about the time **DURING** the later years transition. What were 1 or 2 things that worked well?
10. Think about the time **DURING** the later years transition. What were 1 or 2 things that didn't work during that transition process?
11. Think about the time **DURING** the later years transition. What were 1-2 **resources** you wish you had to assist in the process?
12. If you have a later years transition plan or have done some planning, tell us a little bit about the plan to replace the natural caregiver(s) -- typically responsible for supporting decision making, coordination of benefits, and ensuring physical and emotional wellbeing. The following person(s) has been identified to take on this role.
13. If you have a later years transition plan or have done some planning, what elements of your plan have you documented or begun to document / create a record that can be referenced)?

The next set of questions relates to NEEDS during this transition period and beyond

14. What services/supports are you **MOST** concerned about continuing seamlessly after transition?

15. How important is each of the following **technical support resources** to ensure successful later years transition planning and beyond
16. How important is each of the following **service-oriented resources** to ensure successful later years transition planning and beyond?
17. How important is each of the following **training and planning tools** to ensure successful later years transition planning and beyond?
18. What core team members do you plan to include in your Circle of Care to sustain your desired lifestyle and ensure that the later years transition plan will be implemented?
19. What best describes "your vision" for the Future living arrangements (housing) for the person with I/DD
20. What other information would you like to share about your later years transition planning

The next set of questions relates to CHALLENGES and BARRIERS that you may face during the later years transition period and beyond.

21. The following is a list of potential barriers to **starting** later years transition planning **related to family considerations**. Please indicate the degree to which this has been a concern for you.
22. The following is a list of potential barriers to **starting** later years transition planning **related to personal or system considerations**. Please indicate the degree to which this has been a concern for you.
23. The following is a list of potential challenges in **implementing** a later years transition plan **related to plan management**. Please indicate the degree to which this has been a concern or you anticipate it will be a concern.
24. The following is a list of potential challenges in **implementing** a later years transition plan **related to managing services and staff**. Please indicate the degree to which this has been a concern or you anticipate it will be a concern.
25. The following is a list of potential challenges in **implementing** a later years transition plan **related to optimizing health and wellbeing**. Please indicate the degree to which this has been a concern or you anticipate it will be a concern.
26. This question relates to **people who are self-directing their waiver**. In your experience, rate how much you agree or disagree that the item is a challenge to implementing your current plan. **SKIP THIS Question if you are not self-directing your waiver.**
27. What other information would you like to share **about challenges** and barriers you may face during the later years transition period and beyond?

28. Please share any additional comments about **later years transition planning in general** that you would like us to know about.

This last set of questions asks about SOCIO-DEMOGRAPHIC information about the person with I/DD and their natural caregiver(s).

29. What is the gender of the person with I/DD?
30. What is the disability of the person with I/DD?
31. What level of support does the person with I/DD need? Where direct support enables participation in communities and workplaces and helps with activities of daily living. Some people need continuous supports while others need partial support (periodic coaching and/or direct or support for specific activities).
32. The person with I/DD requires these services? (*check all that apply*) (Overnight, Behavioral, Nursing, Other)
33. How old is the person with I/DD in years?
34. How old is the natural caregiver in years? If there is more than one natural caregiver, give the age of the older caregiver
35. What racial background best describes the person with I/DD?
36. What is the ethnicity of the person with I/DD?
37. Please choose which best describes the current living situation of the person with I/DD (where type of housing does the person live in)
38. What is the total annual household income (of the natural caregiver(s))?
39. What is the highest level of education completed of the natural caregiver(s)?
40. In what County does the person with I/DD live?
41. I would like to receive a copy of the **Sustainability Planning Project** report when the project is completed (Spring 2025). My Email address is_____
42. If you are self-directing your services, have transitioned and would like to participate in a virtual listening session on this topic, share your email address for more information.