

## **APPENDIX C.**

# **CASE STUDY DISCUSSION GUIDES**

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| MO | FL |
| OR | TN |
| AL | PA |

**Support Waivers for People with Intellectual and Developmental Disabilities:  
Core Elements Protocol**

**Respondent** \_\_\_\_\_ **Phone:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**Position:** \_\_\_\_\_ **Date:** \_\_\_\_\_

**Supports Waiver (s):** \_\_\_\_\_

**Discussion Leader:**

- ✓ Explain the purpose of the project.
- ✓ Identify HCBS waiver(s), distinguishing between the comprehensive and support waiver.
- ✓ Explain that this inquiry focuses on the supports waiver in order to secure operational details that describe how the waiver works.
- ✓ Probe when appropriate for major differences between the supports waiver and the comprehensive waiver (e.g., service planning or risk assessment)

**1. How are potential enrollees/families informed about the supports waiver?**

- Collect printed materials to describe the process       None Available

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**2. How do individuals apply for the waiver?**

- Collect printed materials to describe the process       None Available

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

**3. Does the state maintain a separate waitlist (interest list) for the supports waiver?**

- No (Go to Item 4)       Yes →

|             |                               |             |                               |
|-------------|-------------------------------|-------------|-------------------------------|
| 2006: _____ | <input type="radio"/> No info | 2004: _____ | <input type="radio"/> No info |
| 2005: _____ | <input type="radio"/> No info | 2003: _____ | <input type="radio"/> No info |

**4. Does the state maintain a separate waitlist (interest list) for the comprehensive waiver?**

- No (Go to Item 5)       Yes →

|             |                               |             |                               |
|-------------|-------------------------------|-------------|-------------------------------|
| 2006: _____ | <input type="radio"/> No info | 2004: _____ | <input type="radio"/> No info |
| 2005: _____ | <input type="radio"/> No info | 2003: _____ | <input type="radio"/> No info |

5. Does the state maintain a single, consolidated waitlist for all waiver services?  
(NOTE: This should match up with responses to previous questions... check to see probe of not)

- No No waitlist information
- Yes How many people are on the consolidated wait list?
  - 2006 \_\_\_\_\_  No information
  - 2005 \_\_\_\_\_  No information
  - 2004 \_\_\_\_\_  No information
  - 2003 \_\_\_\_\_  No information

6. How does the state track the status of people who want to be in the waiver but for whom slots are not available? [e.g., via case management?]  No tracking done  Don't Know

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7. What is the average time on the waiting or interest list before an individual is enrolled?

- 90 days or less
- 3-12 months
- 1-2 years
- More than 2 years
- No information

8. How are people selected for enrollment?

- Collect printed materials to describe the process
- None Available

Further explanation: \_\_\_\_\_

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9. Is there descriptive information that profiles people served in the supports waiver? (e.g., age, primary disability, living arrangement, functional status, caregiver status?)

- Collect printed materials on profiles
- None Available

Further explanation: \_\_\_\_\_

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10. Is there systematic (not anecdotal) information about the impact of the supports waiver on participant functional status, costs, quality of care, the long-term care system, etc.?

- Collect printed materials on profiles                       None Available

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

11. Has there been an formal evaluation of the supports waiver? If not, is one planned?

- No      If no, probe for how the state knows whether the waiver is effective.  
 Yes      If Yes, collect any printed or electronic information.

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

12. How are individual service plans developed?

- Collect printed materials to describe the process                       None Available

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

13. Does the waiver provide a budget allocation to individuals?

- Yes                       No                       Don't Know

If Yes...how is the budget amount determined? \_\_\_\_\_  
\_\_\_\_\_

If Yes...does the individual have knowledge of the allocation BEFORE planning?    Yes    No  
\_\_\_\_\_

If Yes ... What decision-making authority do individuals/families have over the budget?  
\_\_\_\_\_

14. Who has **primary** responsibility for developing the service plan? (If various staff positions are responsible, probe to determine if a particular party is most frequently responsible)

- State case managers or service coordinators
- County case managers or service coordinators
- Independent case managers or service coordinators
- Consumer-selected personal agents or brokers
- Service provider staff, including case managers employed by providers
- Other \_\_\_\_\_

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

15. Among the service planners, what is:

- a. The average caseload? \_\_\_\_\_ individuals per service planner in \_\_\_\_\_ (year)
- b. The range during this period? From \_\_\_\_\_ to \_\_\_\_\_ individuals per planner.

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

16. Do people have **paid** outside assistance available to them during the planning process to help design the service plan?

- No
- Yes If Yes, collect any printed or electronic information.

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**17.** Does service planning include a distinct risk assessment process to identify and address identified risks?

- No
- Yes

If Yes, ask whether negotiated risk agreements are used.

If Yes, collect any printed or electronic information.

If Yes, is the process the same or different from that used in the comprehensive waiver?

- Same
- Different.... Describe difference...

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**18.** Describe what happens to individuals when they need more support than the waiver can offer, either by way of particular services and/or overall cost? What parameters govern transition from the supports waiver to the comprehensive waiver?

- Collect printed materials to describe the process
- None Available

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**19.** Under what circumstances would an individual be disenrolled from the supports waiver?

- Collect printed materials to describe the process
- None Available

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

20. Describe the process that an individual must follow to change service providers.

- Collect printed materials to describe the process       None Available

Further explanation:

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21. Describe the principle features of the waiver's Quality Assurance/Quality Management System.

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22. Is the Quality Assurance/Quality Management System for the supports waiver the same as the comprehensive waiver or different and, if it is different, how?

- Same    Different

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23. Describe the process that an individual must follow to file a complaint.

- Collect printed materials to describe the process       None Available

Further explanation: \_\_\_\_\_

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24. How are complaints resolved?

- Collect printed materials to describe the process       None Available

Further explanation: \_\_\_\_\_

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25. Describe the process that is used to monitor the health and well-being of individuals participating in the supports waiver.

- Collect printed materials to describe the process       None Available

Overall approach: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

How often is monitoring performed? \_\_\_\_\_

What is the minimum requirement for face-to-face monitoring?     None  
\_\_\_\_\_

Explain any differences between the approach to supports waiver monitoring and comprehensive waiver monitoring.

- No difference     Different

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

26. Describe the process used to follow-up when monitoring reveals problems.

- Collect printed materials to describe the process       None Available

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

27. Does the state expect to change the supports waiver within the next 12 month?

- Yes       No       Don't Know

If YES, please describe the changes that are planned:

Further explanation: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

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|----|----|
| MO | FL |
| OR | TN |
| AL | PA |

**Support Waivers for People with Intellectual and Developmental Disabilities:  
Case Study Discussion Protocol**

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**Respondent** \_\_\_\_\_ **Phone:** \_\_\_\_\_ **Email:** \_\_\_\_\_

**Affiliation:**  State Staff \_\_\_\_\_  ADD Network: \_\_\_\_\_  
 Advocacy Organ. \_\_\_\_\_  Other \_\_\_\_\_

**Date:** \_\_\_\_\_ **Discussion Leader:** JA GS JF

**Supports Waiver(s):** \_\_\_\_\_

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**Discussion Guide:**

- ✓ Explain the purpose of the project
  - ✓ Describe the HCBS waiver(s) in operation, distinguishing between the comprehensive and support waiver.
  - ✓ Explain that this inquiry pertains ONLY to the supports waiver.
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1. What is your understanding of the major policy goals of this supports waiver?

Cost containment/ Budget Goals: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Wait List / Demand Goals: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Consumer Direction/Person Centered Planning Goals: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Rebalancing the long-term care system: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Refinance community services: \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

Respond to a lawsuit: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Other Goals: \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**In these next questions** we'll ask for **your opinion** about various operations pertaining to the waiver. The topic areas include (a) access, (b) service planning, (c) service delivery and safeguards, and (d) satisfaction with outcomes.

**Access** refers to how easily people can apply for and gain admission to the supports waiver.

2. How do potential enrollees/families learn about this supports waiver program?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

3. Is the supports waiver publicized?

Very well       Somewhat       No       Don't Know

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

4. How do individuals apply to the program?

\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

5. How easy is it to apply for the waiver? Is it:

- Very Easy       Somewhat Easy       Neither       Somewhat hard       Very hard       Don't Know

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6. How would describe demand for this waiver among people with I&DD?

- Increasing a lot       Increasing Somewhat       Neither       Decreasing somewhat       Decreasing a lot       Don't Know

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7. Are there any particular issues pertaining to access to the supports waiver that you want to tell us about?

Strengths of the approach to access... Shortcomings?

Are these issues long-standing or are they of relatively recent origin?

- Yes       No       Don't Know

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**Service Planning** refers to the process to develop individual support plans for waiver recipients.

8. Overall, does the planning process encourage individual to:

- a. lead the planning process       Very much       Somewhat       Not at all       DK
- b. define their own service needs       Very much       Somewhat       Not at all       DK
- c. choose the agencies or support givers to offer the needed support?       Very much       Somewhat       Not at all       DK

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9. How well do service planners know the individuals they are planning for? (probe about case loads, frequency of visiting with individuals...)

- Very well     Somewhat     Not at all     Don't Know

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10. Does this waiver make available a supports broker or personal agent to assist individuals to put together the plan and/or negotiate services for the individual? If YES, probe utility/value of this support.

- Yes     No     Don't Know

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11. To what extent do people exercise choice and control over service plans

- A lot     Somewhat     Not much     Don't Know

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12. Are the services available through this waiver broad enough to meet participant needs?

- Generally, Yes  
for most clients     Somewhat  
there are clear exceptions  
e.g. dual dx, older clients     Generally, No  
not for most clients     Don't Know

If not "generally," probe further: \_\_\_\_\_

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13. How easy is it for clients to change their service plans?

- Very Easy     Somewhat Easy     Neither     Somewhat hard     Very hard     Don't Know

If not "very easy," probe further: \_\_\_\_\_

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14. Are there any particular issues pertaining to individual planning that you want to tell us about? Strengths of the approach to individual planning ... shortcomings? Are these long-standing issues or of relatively recent origin?

- Yes       No       Don't Know

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**Service Delivery and Safeguards** refers to the services that individuals received and their operations, and the safeguards in place to assure health and well-being.

15. Once services are authorized, how easy is it for individuals to get these services?

- Very Easy       Somewhat Easy       Neither       Somewhat hard       Very hard       Don't Know

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16. Does this waiver make services available that effectively support individuals to:

- a. Seek/acquire/hold integrated employment       Generally Yes       Somewhat       Generally No       DK
- b. Live on their own or with friends.       Generally Yes       Somewhat       Generally No       DK
- c. Participate in community events       Generally Yes       Somewhat       Generally No       DK

Probe to understand if waiver services are used to promote community integration versus services that are more traditional (sheltered work, enclaves, segregated activities...)

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17. How easy is it for individuals to change service providers?

- Very Easy       Somewhat Easy       Neither       Somewhat hard       Very hard       Don't Know

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18. Generally, would you say it takes days, weeks or months to change service providers?

- Days       Weeks       Months/more       Don't Know

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19. Can waiver recipients generally hire and manage their own support workers?

- Yes       No       Don't Know

If Yes... What percentage of participants hire workers? What are the arrangements? (e.g., fiscal/employer agent, agency with choice) Do they have general choice, a fiscal/employer agent? Do they get the workers from agencies, registries, etc.?

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20. Where "in-home" supports are offered to adults living home with family would you say that the services are primarily family directed, person directed, or both?

- Family Directed       Person Directed       Both       Don't Know

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21. Is a fiscal intermediary or payroll service available to help the individual control or manage the amount allocated for his or her services?

- Yes       No       Don't Know

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22. Is the Quality Assurance/Quality Management System the same as the comprehensive waiver or different and, if it is different, how?

- Same       Different       Don't Know

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23. Do individuals have avenues to file complaints?

- Yes       Somewhat       No       Don't Know

With whom would they? \_\_\_\_\_

Explain further: \_\_\_\_\_

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24. Are these complaints generally handled promptly and appropriately?

- Yes       Somewhat       Not so well       Not at all       Don't Know

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25. To assure the health and well-being of participants, in your opinion, of the safeguards that are in place, which ones are they working well, not working as well, or could be in place but are not?

| Safeguards working well | Safeguards not working well | Safeguards that could be in place, but are not |
|-------------------------|-----------------------------|--|
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |
| _____                   | _____                       | _____  |

## Concluding thoughts... on various topics

26. Thinking about the primary goals you mentioned, in your opinion how successful has this waiver been at meeting these goals?

Goal 1: \_\_\_\_\_

Very       Somewhat       Not at all       Don't Know

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Goal 2: \_\_\_\_\_

Very       Somewhat       Not at all       Don't Know

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Goal 3: \_\_\_\_\_

Very       Somewhat       Not at all       Don't Know

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Goal 4: \_\_\_\_\_

Very       Somewhat       Not at all       Don't Know

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Goal 5: \_\_\_\_\_

Very       Somewhat       Not at all       Don't Know

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27. What are the barriers to achieving the waiver's goals?

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28. What are the waiver's greatest strengths?

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29. What are the TOP THREE things that could be done to improve the waiver?

1. 

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2. 

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3. 

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**OTHER NOTES:**

# **GAUGING THE USE OF HCBS SUPPORT WAIVERS FOR PEOPLE WITH INTELLECTUAL AND DEVELOPMENTAL DISABILITIES: FINAL PROJECT REPORT**

## Files Available for This Report

### Main Report

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr.pdf>

### Appendix A. State-by-State Supports Waiver Profiles

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendA.pdf>

### Appendix B. State-by-State Case Study Results

HTML: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.htm>

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendB.pdf>

### Appendix C. Case Study Discussion Guides\*

PDF: <http://aspe.hhs.gov/daltcp/reports/2007/gaugingfr-appendC.pdf>

\* This Appendix is currently not available as an HTML file.