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: ________  ○ No info  2004: ________  ○ No info
     - 2005: ________  ○ No info  2003: ________  ○ No info

4. Does the state maintain a separate waitlist (interest list) for the comprehensive waiver?
   - No (Go to Item 5)  ✔ Yes
     - 2006: ________  ○ No info  2004: ________  ○ No info
     - 2005: ________  ○ No info  2003: ________  ○ 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  _________  O  No information
  2005  _________  O  No information
  2004  _________  O  No information
  2003  _________  O  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?]  O  No tracking done  O  Don’t Know

_________________________________________________________________________________
_________________________________________________________________________________

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

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

8. How are people selected for enrollment?

- Collect printed materials to describe the process  O  None Available

Further explanation: ______________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________

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  O  None Available

Further explanation: ______________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
_________________________________________________________________________________
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 a 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: _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

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
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

23. Describe the process that an individual must follow to file a complaint.
   - Collect printed materials to describe the process
   - None Available
   Further explanation: _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

24. How are complaints resolved?
   - Collect printed materials to describe the process
   - None Available
   Further explanation: _______________________________________________________
   _______________________________________________________
   _______________________________________________________
   _______________________________________________________

C-6
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 months?

- Yes
- No
- Don’t Know

If YES, please describe the changes that are planned:

Further explanation: __________________________________________________________
__________________________________________________________________________
__________________________________________________________________________
Support Waivers for People with Intellectual and Developmental Disabilities:
Case Study Discussion Protocol

Respondent ______________________ Phone: __________________ Email: ________________________

Affiliation:  ○ State Staff ___________________________  ○ ADD Network: _______________________
             ○ Advocacy Organ. ______________________  ○ Other ______________________________

Date: _______________  Discussion Leader: JA  GS  JF

Supports Waiver(s): ________________________________________________________________

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.

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: ______________________________________________________
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

   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

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

   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

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

   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

**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

   __________________________________________________________________________
   __________________________________________________________________________
   __________________________________________________________________________

C-10
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

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

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

- A lot
- Somewhat
- Not much
- Don’t Know

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:

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:
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

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

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…)

C-12
17. How easy is it for individuals to change service providers?

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

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

- Days
- Weeks
- Months/more
- Don’t Know

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.?

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

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
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

23. Do individuals have avenues to file complaints?

- Yes
- Somewhat
- No
- Don’t Know

With whom would they? 

Explain further:

24. Are these complaints generally handled promptly and appropriately?

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

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?

<table>
<thead>
<tr>
<th>Safeguards working well</th>
<th>Safeguards not working well</th>
<th>Safeguards that could be in place, but are not</th>
</tr>
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<tbody>
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</table>
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
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Goal 2: _______________________________________________________
   ○ Very    ○ Somewhat    ○ Not at all    ○ Don’t Know
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Goal 3: _______________________________________________________
   ○ Very    ○ Somewhat    ○ Not at all    ○ Don’t Know
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Goal 4: _______________________________________________________
   ○ Very    ○ Somewhat    ○ Not at all    ○ Don’t Know
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

Goal 5: _______________________________________________________
   ○ Very    ○ Somewhat    ○ Not at all    ○ Don’t Know
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
27. What are the barriers to achieving the waiver’s goals?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

28. What are the waiver’s greatest strengths?
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

29. What are the TOP THREE things that could be done to improve the waiver?
1. _____________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
2. _____________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________
3. _____________________________________________________________________
_______________________________________________________________________
_______________________________________________________________________

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

Appendix A. State-by-State Supports Waiver Profiles

Appendix B. State-by-State Case Study Results

Appendix C. Case Study Discussion Guides*

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