

CANDIDATE INDICATORS Revised 10/31/97		DATA SOURCE
Note: All indicators will be reported for the past year or point-in-time, unless otherwise noted.		
DOMAIN: CONSUMER OUTCOMES		
<u>Working¹ - Concern: People receiving vocational supports find and maintain employment in integrated settings and earn increased wages.</u>		
1. The average hourly wage of people in vocational programs. ²		Provider survey
2. The average number of hours worked per week (for those weeks worked) in the previous year.		Provider survey
3. The average number of weeks worked in the previous year.		Provider survey
4. The percent of people earning above and below minimum wage. ³		Provider survey
5. Average duration of time in this job for people who are employed.		Provider survey
<u>Community Inclusion - Concern: People use integrated community services.</u>		
6. The proportion of people who use community/public services and facilities such as banks, post offices, hairdressers, places of worship, and medical services.		Consumer survey
<u>Choice/Self-Determination - Concern: People make life choices and participate actively in planning their services and supports.</u>		
7. The proportion of people who make choices about important life decisions, such as: ⁴		Consumer survey
a) Housing		
b) Roommates		
c) Daily routines		
d) Support staff or provider (residential, work, service coordination)		
e) Social and recreational activities		
8. The proportion of people reporting that their service plan reflects/includes/is about things that are important to them.		Consumer survey
<u>Supporting Families⁵ - Concern: Families improve their capacity to provide support for family members living at home.</u>		
9. The percentage of families with an adult family member living in the home who report satisfaction with the supports they receive.		Family survey

¹ This data will be collected only for state DD clients receiving employment services from DD or VR agencies. Work is defined as *paid* work, not including volunteer work. Indicators will be reported out by employment categories.

² Point in time measurement.

³ Point in time measurement.

⁴ A scale may be constructed to measure this indicator.

<p><u>Independence - Concern: People experience personal growth and increased independence.</u></p> <p>10. The proportion of people reporting access to adaptive equipment, environmental modifications, and assistive communication devices.</p> <p>11. The proportion of people reporting that they control their own income and earnings and spending money.</p>	<p>Consumer survey</p> <p>Consumer survey</p>
<p><u>Relationships - Concern: People gain and maintain friendships and relationships.</u></p> <p>12. The proportion of people who report having friends and caring relationships with people other than those in the service system (e.g. paid staff, co-workers in segregated settings, and roommates with disabilities).</p> <p>13. The proportion of people who report having someone they can talk to about private matters.</p> <p>14. The proportion of people who are able to see their families and friends when they want to.</p> <p>15. The proportion of people reporting feeling lonely.</p>	<p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p>
<p><u>Quality of Life - Concern: People are satisfied with the supports they receive and experience a high quality of life.</u></p> <p>16. The proportion of people in current residential arrangements who express a desire to stay vs. a desire to move.</p> <p>17. The proportion of people reporting satisfaction with their job, day program, or school.</p> <p>18. The proportion of people reporting that they worked as much or as long as they wanted to.</p> <p>19. The proportion of people reporting that they received support to learn or do something new that was important to them.</p> <p>20. The proportion of people who report having adequate transportation when they want to go somewhere.</p>	<p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p>
<p style="text-align: center;">DOMAIN: SYSTEM PERFORMANCE</p> <p><u>Service Coordination - Concern: Service coordinators are accessible and support consumer participation in service planning.</u></p> <p>21. The proportion of people who are able to see their service coordinators when they want to.</p> <p>22. The proportion of people who report that they participated in the development of their service plan.</p>	

⁵ The family survey will target families a) who have an adult family member living at home *and* b) who are receiving any type of service, including service coordination.

Utilization and Expenditures⁶ - Concern: People are being served in a manner which aligns with public developmental disability agency goals (including self-determination, inclusion, and natural supports) and resources.

23. The average annual expenditure per person overall, by living arrangement, type of service and category of support.	System
24. The annual expenditure for each living arrangement, type of service and category of support, as a percent of total expenditures.	System
25. The range of annual per person expenditures, by living arrangement, type of service and category of support.	System
26. The amount expended on vocational services compared to wages of people receiving vocational services by type of service.	System
27. The number of persons, age-adjusted and risk-adjusted, receiving services and supports by type of living arrangement:	System
<ul style="list-style-type: none"> • Large (>16) State-Operated Residential Facilities • Large (>16) Privately-Operated Residential Facilities • Medium (7-15) Public/Private Residential Licensed Group Home Facilities • Small (<6) Public/Private Licensed Residential Group Home Facilities • Foster Care/Family Home Settings • Other Residential Programs Owned/Operated by Public/Private Agencies (Apartments) (Non-consumer controlled housing) • In-Home Supports furnished to primary consumers in their own residence (supported living) • Family Support (services delivered in the family home; cash subsidies) • Service Coordination/Case Management • Facility-Based Vocational Services (Sheltered Workshops, Work Activity Centers) • Group Vocational/Employment Services (enclaves and mobile crews) • Individual Integrated Employment Supports (supported employment, job coach model) • Facility-Based Non-Vocational Services (day habilitation, day treatment, "seniors programs", etc.) • Non-Facility Based/"Non residential" community participation/training services • Other community integrated activities (e.g., health club memberships, etc.) • Clinical services (therapies, behavior management, psychological services and so forth) 	

⁶ Includes public expenditures only.

Access - Concern: People are informed about available resources and those eligible have access to an adequate complement of services and supports.

28. The proportion of people reporting that they know whom to ask for information about services.	Consumer survey
29. The percentage of people indicating that location of services and supports are convenient.	Consumer survey
30. The rate at which people report that "needed" services were not available.	Consumer survey
31. The average time period: ⁷ <ul style="list-style-type: none"> • from intake to eligibility determination • from eligibility determination to first plan of care • from first plan of care to initial service authorization⁸ • from intake to initial service authorization. 	System
32. The proportion of people served who are members of racial and ethnic groups relative to the proportion of such individuals in the general population of the service area.	System
33. The number of persons (unduplicated count), age-adjusted, receiving one or more services or supports.	System
34. The number of persons (unduplicated count), age-adjusted, in service per 100,000 general population.	System
35. The number of persons on waiting list for services/ supports needed currently, by age, by living arrangement (living with family vs. not living with family), and by service status (in service vs. not in service ⁹), relative to the total service population.	System
36. The proportion of people reporting that they can call their advocates, or guardians as often as they like.	Consumer Survey

**DOMAIN
HEALTH, WELFARE, & RIGHTS**

Safety - Concern: The system ensures that people are safe from abuse, neglect, and injury.

37. The mortality rate of the MR/DD population compared to the general area population, by age, by cause of death (natural or medicolegal ¹⁰), and by MR or DD diagnosis. ¹¹	System
38. The incidence of major or serious injuries among people with MR/DD in the course of service provision. ¹²	System

⁷ Field test states will collect data according to these breakouts; the committee will select from among them based on the test.

⁸ Applies only to those persons authorized, not waitlisted, for service.

⁹ In service includes persons receiving DD services/supports in addition to service coordination (or cash/ vouchers for those services/supports).

¹⁰ Medicolegal deaths include homicide, suicide, and accidents.

¹¹ States with historical mortality data will report data by age, sex, ethnicity, and cause for the past five years in order to build a database of sufficient size to yield reliable rates.

39. The proportion of people who were victims of selected crimes reported to a law enforcement agency during the past six months, by type of crime (rape, sexual assault, personal robbery, aggravated and simple assault, household burglary, and theft). ¹³	System
40. The proportion of people who report that they feel safe in their home and neighborhood.	Consumer survey
<u>Health - Concern: People secure needed health services.</u>	
41. Number of days in the past month people report that their normal routines were interrupted due to illness.	Consumer survey
42. Period since last physical exam. ¹⁴	System/ Consumer survey
43. Period since last OB/GYN exam.	System/ Consumer survey
44. The percentage of people who have a primary care physician.	System/ Consumer survey
45. Period since last routine dental exam.	System/ Consumer survey
<u>Concern: Medications are administered safely and appropriately.</u>	
46. The proportion of people receiving psychotropic medications, with or without a psychiatric diagnosis. ¹⁵	System
<u>Concern: The system makes limited use of restraints or other restrictive practices.</u> ¹⁶	
<ul style="list-style-type: none"> • Frequency of use of mechanical restraints. • Frequency of use of emergency chemical restraints. 	System

¹² Injuries can be classified into two general categories, minor and serious. *Serious* refers to injuries requiring medical treatment.

¹³ This data will be collected on crimes reported in incident reports. Additional data will be collected through the consumer survey (see indicator #40).

¹⁴ Kaiser Permanente Preventative Care Guidelines for Adult Comprehensive Health Assessment, based on recommendations of the American College of Physicians and the US Office of Disease Prevention, are as follows: Age 18-45: Every 3 years; Age 50-65: Every 2 years; Age 65+: Yearly.

¹⁵ For people receiving residential supports only.

¹⁶ The committee agreed that project staff would do a survey of state policies on mechanical and chemical restraints this year and develop indicators for version 2.0. These are suggested indicators and definitions for future consideration. According to the Oklahoma Physical Status Review Manual, Draft 3/7/97, mechanical restraints are defined as the restriction of movement. Chemical restraint is defined as the use of any drug to restrict function or movement. It is useful to differentiate between drugs used in emergency situations to control behavior vs. drugs used prior to medical or dental procedures to reduce pain or anxiety.

<p><u>Respect/Rights - Concern: People receive the same respect and protections as others in the community.</u></p> <p>47. The proportion of people who feel that their rights are respected by others.</p> <p>48. The proportion of people who have attended activities of self-advocacy groups or other groups that address rights.</p> <p>49. The proportion of people reporting satisfaction with amount of time alone.</p>	<p>Consumer survey</p> <p>Consumer survey</p> <p>Consumer survey</p>
<p style="text-align: center;">DOMAIN PROVIDERS</p> <p><u>Acceptability - Concern: The system is sensitive to consumer preferences and demands.</u></p> <p>50. The proportion of direct service providers who have consumers on their boards or advisory committees.¹⁷ (Also measure <i>number</i> of consumers on boards and <i>total size</i> of boards, if applicable.)</p> <p>51. The proportion of providers who have family members on their boards or advisory committees. (Also measure <i>number</i> of family members on boards and <i>total size</i> of boards, if applicable.)</p> <p>52. The proportion of people who are informed about and satisfied with the grievance process.</p> <p>53. The proportion of people indicating that staff were sensitive to their disability.</p>	<p>Provider survey</p> <p>Provider survey</p> <p>Consumer survey</p> <p>Consumer survey</p>
<p><u>Stability - Concern: Direct contact staff turnover ratios and absentee rates are low enough to maintain continuity of supports and efficient use of recruitment and training resources.¹⁸</u></p> <p>54. The crude separation rate, defined as the proportion of direct contact staff separated in the past year.</p> <p>55. The average length of service for all direct contact staff who separated in the past year.</p> <p>56. The vacancy rate, defined as the proportion of full time, direct contact positions that were vacant as of a specified date.</p> <p>57. The proportion of people who have changed residences more than once in the past year.</p> <p><u>Concern: Providers must have adequate and stable financial resources in order to provide services.</u></p> <p>58. Current ratio: the ratio of current assets to current liabilities.¹⁹</p> <p>59. Total liabilities to net worth.</p> <p>60. Total assets to liabilities.²⁰</p>	<p>Provider survey</p> <p>Provider survey</p> <p>Provider survey</p> <p>Consumer survey</p> <p>System</p> <p>System</p> <p>System</p>

¹⁷ For indicators 50-51, the denominator would be the total number of direct service providers. Service providers are defined as agencies serving more than 10 people.

Staff Qualifications/Competency - Concern: Direct care staff are properly screened and are supported to develop competencies necessary for providing services.	
61. The proportion of providers with staff available who can communicate with individuals who use modes of communication other than spoken English.	Consumer survey

¹⁸ Direct contact staff are defined as employees who spend at least 50% of their time providing hands on, face-to-face contact with consumers. It excludes psychologists, nurses, and others whose primary job duties are not the provision of direct care, as well as managers/supervisors who are responsible for the supervision of staff.

¹⁹ Restricted as well as non-restricted assets should be included as part of these figures.

²⁰ Restricted as well as non-restricted assets should be included as part of these figures.

Table 1

Summary of Required Evaluation Components and Proposed Data Collection/Data Integration

Components (RFP page no.)	Consumer Survey	Provider Survey	Case Man. Survey	Family Survey	State MMIS	Qualitative Interview
I: Consumer Outcomes						
A. "Measure consumer outcomes related to" (p. 3)						
1. satisfaction with services (p.3)	X			X		X
2. choice/self-determination (p.3)	X	X	X	X		X
3. independence (p.3)	X	X	X	X		X
4. support of families and relationships (p.3)	X	X	X	X		X
5. quality of life (p.3)	X	X	X	X		X
B. "Consumer data...will include" (p.5)						
6. integrated community services (p.5)	X			X		
7. self-determination						
a. life choices (p.5)	X			X		
b. participation in planning (p.5)	X	X	X	X		
c. improving family capacity to support members at home (p.5)	X		X	X		
d. adequate complement of services/supports (p.5)	X		X	X		
e. appropriate modes of communication (p.5)	X	X	X	X		
C. "Health, welfare and rights" (p.3)						
1. consumer safety (p.3)	X	X	X	X		
2. health (p.3)	X	X	X	X		
3. medical needs/medication administration (p.3)	X	X	X	X		
4. respect (p.3)	X	X	X	X		
5. rights (p.3)	X	X	X	X		
6. access for racial/ethnic minorities (p.3)			X		X	X
7. understand option to choose ICF-MR (p.3)	X		X	X		
II. Provider Performance (in addition to Consumer Outcomes)						
A. "Provider data...including (p.4)						
1. sensitivity to consumer preferences/demands (p.4)	X	X	X	X		
2. continuity of supports (p.4)	X	X	X	X		
3. absentee rates (p.4)		X				
4. staff turnover rates (p.4)	X	X		X		
5. use of recruitment (p.4)	X	X		X		
6. screening direct support staff (p.5)		X				
7. training resources (p.4)		X	X			
8. provision of training		X				
a. medication administration (p.4)		X	X		X	
b. meeting health care needs (p.5)	X	X	X	X		
c. other	X	X	X	X		X
9. supports to develop service delivery competencies (p.5)		X	X			
10. licensing violations, VA reports, etc. (p.4)					X	
III. HCBS Program Performance (in addition to Consumer Outcomes and Provider Performance)						
A. "Evaluate...the waiver" on:						
1. quality of care (p.4)	X	X	X	X	X	
2. access to HCBS (p.4)	X	X	X	X	X	X
3. cost-effectiveness of HCBS (p.4)	X	X	X	X	X	
B. Include "both urban and rural areas" (p.4)	X	X	X	X	X	X
IV. Best Practices Identification (p.5)		X	X	X		X

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A Collaboration of:

National Association of State
Directors of Developmental
Disabilities Services, Inc.
Alexandria, VA

Human Services
Research Institute
Cambridge, MA

Co-Directors

Gary Smith
Director of Special Projects
NASDDDS
9043 W. Cross Drive
#14-206
Littleton CO 80123
303.973.6210
Fax: 303.727.6891
chromedome@uswest.net

John W. Ashbaugh
Senior Vice President
Human Services
Research Institute
2336 Massachusetts Ave.
Cambridge MA 02140
617.876.0426 (ext. 314)
Fax: 617-492-7401
Honer1@aol.com

Project Memo: 99-19
Date: March 10, 1999

TO: CIP Phase II Steering Committee
FROM: Gary Smith
RE: System Indicators/Provider Survey

Attached to this memo, please find a listing of the CIP Phase I "system indicators", measures, and data collection protocols. This listing is provided for reference.

Most of these system indicators have been addressed in other project memos, including implications for data collection. One that has not is a proposed "system responsiveness indicator" (Number 9 on the attached listing (Over the past year, the number of people whom the SDDA was obligated to admit and serve for health and safety reasons). This is a possible substitute for the waiting list indicator. Where we have not issued a project memo concerning any of the other indicators, either no issues had been raised in previous Steering Committee meetings or suggested by the assessment of the Phase I experience. However, Committee members may well wish to raise issues concerning the present indicators or offer suggestions for other indicators at the meeting.

In September, there was discussion concerning the creation of a provider survey instrument. We have deferred creating such an instrument until the Committee made decisions regarding various indicators where changes might be made. A post-meeting activity will be preparing template documents for states to employ in surveying providers concerning various indicators.

the previous year. [3.]	One year period prior to June 30, 1999.	<p>Total number of weeks worked in the previous year (aggregate of all individuals in vocational programs)</p> <p>÷ Total number of individuals in vocational programs</p>	<p>Report out by number of individuals in the following employment categories:</p> <p>(1) group / facility-based programs</p> <p>(2) individual supported employment programs</p> <p>(3) group supported employment programs.</p>	
4. The percent of people earning at or above the state minimum wage of \$ __. ____. [4.]	<p><i>Reporting period:</i></p> <p>As of June 30, 1999.</p>	<p><i>Measure:</i></p> <p>Number of individuals earning at or above minimum wage</p> <p>÷ Total number of individuals employed</p>	<p><i>Protocol:</i></p> <p>Report out by number of individuals in the following employment categories:</p> <p>(1) group / facility-based programs</p> <p>(2) individual supported employment programs</p> <p>(3) group supported employment programs.</p>	

<p>5. Average duration of time in this job for people who are employed. [5.]</p>	<p><i>Reporting period:</i> As of June 30, 1999.</p>	<p><i>Measure:</i> Total number of months worked in current job to date (aggregate of all individuals employed) rounded to nearest month ÷ Total number of individuals employed</p>	<p><i>Protocol:</i> Report out by number of individuals in the following employment categories: (1) group / facility-based programs (2) individual supported employment programs (3) group supported employment programs.</p>	<p><i>Definitions:</i> <i>Seasonal employment</i> is considered interrupted employment -- duration should be counted as total number of months worked; off-season months not worked are not to be counted as months worked.</p>
<p>6. The proportion of people served who are members of racial and ethnic groups relative to the proportion of such individuals in the general population of the service area. [32.]</p>	<p><i>Reporting period:</i> As of June 30, 1999.</p>	<p><i>Measure:</i> Number of individuals served, by census categories of race (Asian or Pacific Islander, Black, American Indian or Alaskan Native, White, Other, Unknown) and ethnicity (Hispanic, Non-Hispanic, Unknown) ÷ Total service population</p>		

7. Number served relative to general population (age adjusted) or Number served relative to SSI and SSDI population disabled due to MR [proposed]	<i>Reporting period:</i> One year period prior to June 30, 1999.			
8. Over the past year, number of people whom the SDDA was obligated to admit and serve for health and safety reasons. [proposed]	<i>Reporting period:</i> One year period prior to June 30, 1999.			
9. The mortality rate of the MR/DD population compared to the general area population, age-adjusted, by cause of death (natural or medicolegal), and by MR or DD diagnosis. [37.]	<i>Reporting period:</i> As much data is available for five years prior to June 30, 1999.	<i>Measure:</i> Number of deaths ÷ Adult MR/DD service population		<i>Definitions:</i> <i>Medicolegal deaths -- include homicide, suicide, and accidents.</i>

10. The incidence of major or serious injuries among people with MR/DD in the course of service provision over the previous year. [38.]	Reporting period: One year period prior to June 30, 1999.	Measure: Number of serious injuries ÷ Total number of people whose injuries are tracked by the state's incident reporting system		Definitions: <i>Serious injury:</i> an injury that requires professional medical treatment.
11. The proportion of people who were victims of selected crimes reported to a law enforcement agency during the past year, by type of crime (rape, sexual assault, personal robbery, aggravated and simple assault, household burglary, and theft). [39.]	Reporting period: One year period prior to June 30, 1999.	Measure: Number of people who were victims of selected crimes reported to a law enforcement agency during the past fiscal year ÷ Total number of people tracked by the state's incident reporting system	Protocol: Break down by type of crime: rape, sexual assault, personal robbery, aggravated and simple assault, household burglary, and theft.	
12. Average period since last physical exam. [42.]	Reporting period: One year period prior to June 30, 1999.	Measure: Number of months since last physical exam (aggregate of all individuals served) ÷ Total number of individuals served		

		<p><i>Additional measure:</i></p> <p>Number of individuals who have had physical exam within the last twelve months</p> <p>÷ Total number of individuals served</p>		
<p>13. Average period since last OB/GYN exam. [43.]</p>	<p><i>Reporting period:</i></p> <p>One year period prior to June 30, 1999.</p>	<p><i>Measure:</i></p> <p>Number of months since last OB/GYN exam (aggregate of all women served)</p> <p>÷ Total number of women served</p>		
		<p><i>Additional measure:</i></p> <p>Number of women served who have had OB/GYN exam within the last twelve months</p> <p>÷ Total number of women served</p>		

14. Percentage of people who have a primary care physician. [44.]	Reporting period: One year period prior to June 30, 1999.	Measure: Number of people who have a primary care physician ÷ Total number of individuals served		
15. Average period since last routine dental exam. [45.]	Reporting period: One year period prior to June 30, 1999.	Measure: Number of months since last routine dental exam (aggregate of all individuals served) ÷ Total number of individuals served		
16. The proportion of people receiving psychotropic medications, with or without a psychiatric diagnosis. [46.]	Reporting period: As of June 30, 1999.	Measure: Number of individuals receiving psychotropic medications ÷ Total number of individuals for whom the state tracks medications		

<p>17. The proportion of direct service providers who have consumers on their boards or advisory committees. [50.]</p>	<p><i>Reporting period:</i> As of June 30, 1999.</p>	<p><i>Measure:</i></p> <p>Number of direct service providers who have consumers on their boards or advisory committees</p> <p>÷ Total number of direct service providers.</p>		<p><i>Definitions:</i></p> <p><i>Direct service providers:</i> agencies serving more than 10 people</p> <p><i>Consumer:</i> primary consumer, i.e. a person with mental retardation or other developmental disabilities who is actually receiving services</p>
		<p><i>Additional measure:</i></p> <p>Number of consumers on boards</p> <p>÷ Total number of board members</p>		
<p>18. The proportion of direct service providers who have family members on their boards or advisory committees. [51.]</p>	<p><i>Reporting period:</i> As of June 30, 1999.</p>	<p><i>Measure:</i></p> <p>Number of direct service providers who have family members on their boards or advisory committees</p> <p>÷ Total number of direct service providers.</p>		<p><i>Definitions:</i></p> <p><i>Family member</i> -- an immediate family member (parent or sibling) of a person receiving services</p>
		<p><i>Additional measure:</i></p> <p>Number of family members on boards</p>		

		÷ Total number of board members		
19. The number of direct contact staff who separated relative to the total number of direct contact staff employed during the period July 1, 1998 to June 30, 1999 (crude separation rate). [54.]		<p><i>Measure:</i></p> <p>Number of direct contact staff who separated</p> <p>÷ Total number of direct contact staff employed during the past year</p>		<p><i>Definitions:</i></p> <p><i>Separation:</i> voluntary or involuntary movement out of an organization (i.e. includes resignations as well as terminations; separations do not include transfers or promotions within an organization)</p> <p><i>Direct contact staff:</i> both full-time and part-time employees whose primary duties include hands-on, face-to-face contact with consumers. This may exclude psychologists, nurses and managers / supervisors whose responsibilities are primarily supervisory in nature.</p>
20. The average length of service for all direct contact staff who separated over the past year. [55.]	<p><i>Reporting period:</i></p> <p>One year period prior to June 30, 1999.</p>	<p><i>Measure:</i></p> <p>Length of employment in months (aggregate)</p> <p>÷ Total number of direct contact staff who separated over the past year</p>	<p><i>Protocol:</i></p> <p>Providers will be asked to submit a list of separated direct contact staff with their dates of hire and departure.</p>	

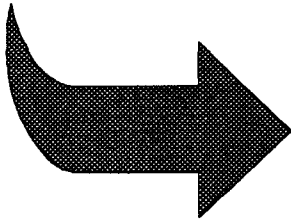
21. Vacancy rate, the number of full-time direct contact positions vacant compared to the total number of full-time direct contact positions. [56.]	Reporting period: As of June 30, 1999.	Measure: Number of full-time direct contact positions that were vacant ÷ Total number of full-time direct contact positions		
		Alternate measure: New measure related to use of overtime hours to cover direct contact shifts (may include a combination of both full and part-time positions).		
22. Current ratio. [58.]	Reporting period: Latest fiscal year available.	Measure: Current assets ÷ Current liabilities	Protocol: States will be asked to submit the necessary figures either by: (1) sending copies of provider financial statements (including income statement <i>and</i> balance sheet) or (2) having a trained accountant extract the specified figures from the statements. Data will be submitted for all provider agencies or for a representative sample of 30% or 50 agencies, whichever is less.	
23. Months of cash reserves. [added in Phase I]	Reporting period: Latest fiscal year available.	Measure: Current assets ÷ Monthly expenses (annual expenditures divided by 12)		
24. Total assets to liabilities. [60.]	Reporting period: Latest fiscal year available.	Measure: Total assets ÷ Total liabilities		

25. Total assets plus accumulated depreciation to total liabilities. [added in Phase I]	Reporting period: Latest fiscal year available.	Measure: Total assets (including depreciated assets) ÷ Total liabilities		
26. Percent of revenues coming from private contributions. [added in Phase I]	Reporting period: Latest fiscal year available.	Measure: Total revenues ÷ Revenues from private sources		

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A Collaboration of:

National Association of State
Directors of Developmental
Disabilities Services, Inc.
Alexandria, VA

Human Services
Research Institute
Cambridge, MA

Co-Directors

Gary Smith
Director of Special Projects
NASDDDS
9043 W. Cross Drive
#14-206
Littleton CO 80123
303.973.6210
Fax: 303.727.6891
chromedome@uswest.net

John W. Ashbaugh
Senior Vice President
Human Services
Research Institute
2336 Massachusetts Ave.
Cambridge MA 02140
617.876.0426 (ext. 314)
Fax: 617-492-7401
Honer1@aol.com

Project Memo: 99-14
Date: March 10, 1999

TO: CIP Phase II Steering Committee
FROM: Sarah Taub
RE: Phase II Family Support Survey

Following, please find the Phase II Family Support Survey. The survey has been revised to correct problems in question wording.

Core Indicators Project – Family Survey

Please provide the following information about your family. All responses will be kept **strictly confidential**.

- a. In what county/region does your family live? _____ (if applicable)
- b. What is your relationship to your family member with a disability?
☐ Parent (natural or adoptive)
☐ Sibling or other relative
☐ Other (specify) _____
- c. What is your family's race?
☐ American Indian/Eskimo/Aleut
☐ Asian/Pacific Islander
☐ Black
☐ White
☐ Other/Unknown _____
- d. What is your family's ethnicity?
☐ Hispanic
☐ Non-Hispanic
- e. What is the age of the primary caregiver? _____
- f. What is the health status of the primary caregiver?
☐ Excellent
☐ Average
☐ Poor
- g. What is the age of the individual with a disability? _____ ☐ Don't know
- h. Are you on a waiting list for services?..... ☐ Yes ☐ No ☐ Don't know
- i. Does your family receive:
Case management/service coordination..... ☐ Yes ☐ No ☐ Don't know
Family Support..... ☐ Yes ☐ No ☐ Don't know
Other services/supports (specify) _____
- j. Does your family member receive:
Case management..... ☐ Yes ☐ No ☐ Don't know
In-home supports..... ☐ Yes ☐ No ☐ Don't know
Vocational services..... ☐ Yes ☐ No ☐ Don't know
Transportation..... ☐ Yes ☐ No ☐ Don't know
Other services/supports (specify) _____

Core Indicators Project – Family Survey

INFORMATION

	Most of the time	Some of the time	Rarely	Don't Know	N/A
1. Do you receive information about services and supports that are available to your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the information easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CHOICE/PLANNING

	Most of the time	Some of the time	Rarely	Don't Know	N/A
3. Do you choose who helps you, such as your service coordinator, case manager, or home support provider?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is turnover of staff that work with you a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do the staff work together with you to identify what you need as a family to support your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do they present you and your family member with a range of options to meet your needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do they respect your choices and preferences?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ACCESS

	Most of the time	Some of the time	Rarely	Don't Know	N/A
8. Do the supports offered reflect the needs of your <i>family</i> as well as your family member with a disability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is your family getting the supports you need, such as respite care, training, or education?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Are supports available when your family wants and needs them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. In a crisis, are supports available in a timely manner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do staff communicate with you in your preferred language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Linkages

	Most of the time	Some of the time	Rarely	Don't Know	N/A
13. Do the staff help you get other supports in your community, such as services offered through vocational rehabilitation programs, recreation departments, churches, or medical services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
14. Do the staff help you find family, friends, or neighbors who can provide some of the supports your family needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Core Indicators Project – Family Survey

Please use the space below for any other comments you would like to make.

Please note: It is our policy to keep all responses to this survey anonymous and confidential. However, if you have a specific concern that needs to be addressed and you would like someone to contact you, **please check here to waive confidentiality:** ☐

What is the best way to contact you? _____

CORE INDICATOR PROJECT OVERVIEW

Community Supports for Minnesotans with Disabilities

Lori Dablow, ph# 651/582-1905

Judy Hauschild, ph# 651/582-1917

Background

- 700,000 persons with developmental disabilities nationwide receive services and supports through public funding
- \$25 billion dollars are spent in federal, state, and local tax dollars to fund these services and supports
- Increasing demands by policymakers and stakeholders to measure and improve performance
- "Buy outcomes rather than programs"
- January 1997 NASDDDS launched this unprecedented multi-collaborative effort to jointly assess and improve performance in partnership with the HSRI

Project Goals

- Develop a solid approach to performance and outcome measurement
 - * Develop nationally-recognized performance and outcome indicators
 - * Benchmark service system performance against levels achieved in other states
 - * Track service system performance and outcomes from year to year
 - * Provide states reliable and meaningful information about service utilization and expenditures

Project Goals

- Improve the delivery of services and supports for persons with developmental disabilities
 - * Gauge system access and responsiveness
 - * Monitor consumer health and personal security
 - * Promote the implementation of person-centered support principles
 - * Monitor systems overall financial health

Project Goals - "Whole person funding"

- Traditional "financial profiles" of state DD systems are based on program by program
- Data collection will provide "whole person funding" levels that permit valid and accurate comparisons of the total costs of serving individuals
- Locate/track all consumer service costs by living arrangement
- Spread program/categorical expenditure data by living arrangement

Project Parameters

- Persons age 18 and older, with plans to include children in future years
- Persons with developmental disabilities, with plans to add persons with other disabilities in future years
- Persons receiving at least one public funded support or service
- Operate in tandem with existing efforts and other performance tracking and monitoring systems (i.e. DT&H surveys)

Phase I - Creating a Performance Monitoring System

- Identify common performance indicators - 61 "candidate indicators"
- Candidate indicators categorized among five areas of "domains"
 - * Consumer Outcomes - self determination, inclusion, independence
 - * Utilization and Expenditures of public dollars
 - * System Response, Service Availability and Access
 - * Health, Welfare and Rights
 - * Provider Financial Indicators (i.e. stability)

Phase I - Identify Data to Obtain

- Identify data states need to obtain for the measures associated with each indicator
- Develop measure of uniformity in terms of accounting for expenditures
 - * Each state has different program categories and definitions
 - * "Apples to Apples"
 - * "Span of Control"
 - * "Risk Adjusting"

Phase I - Data Collection Strategies

- Design and "field test" of the consumer and family survey instruments
- Seven states "field test" project data collection tools/instruments
 - * Consumer Interview Survey
 - * Family Survey - by mail
 - * Provider Survey
 - * Data from Information Systems

Phase I - Wrap Up

- Evaluated and shared results
- Concluded the project should continue
- Invitation to states to join Phase II

Core Indicator Project - Phase II

- Minnesota joins project
- January 1999 through June 2000
- Preparation for Phase II
 - * Refine candidate indicators
 - * Revise data collection protocols
 - * Improve the consumer survey process e.g. training
 - * Field test revised consumer survey - Kandiyohi County
 - * Streamline with current MR/RC waiver evaluation efforts

Consumer Interview Surveys

- 400 persons per state minimum, random selection
- Persons in all types of living arrangements
- 32-55 minutes average for interview
- Pre-survey form completed prior to interview
- Surveyor feedback form:
 - * Length of interview
 - * Problematic questions
 - * Track number of refusals and reason(s)

Family Survey - By Mail

- 1000 per state minimum, random selection
- Adult family member resides in the family home
- Adult family member resides outside the family home
- Persons living in all types of living arrangements

Provider Survey

- All provider agencies will be asked to complete the survey
- Questions will primarily focus on provider stability:
 - * Staff turnover
 - * Financial stability
 - * Additional misc questions

Advisory Committee

- 30 Stakeholders from counties, provider agencies, advocacy, etc
- May 18th is first meeting
- Develop strategies to streamline the project with other stakeholder requirements and with other quality assurance monitoring efforts.

Project Timelines

- April/May: DHS meets with ARRM, MNDACA, HABCO, County Supervisors
- April/May: Field testing of consumer survey in Kandiyohi County
- May/June:
 - 1) Select consumers for survey
 - 2) Request information from counties necessary to conduct family survey and consumer surveys
 - 3) Meetings with Advisory Committee
- July-Sept: Data collection (consumer, family, provider surveys must be completed by September 30, 1999.
- Oct-Dec: DHS submits data to national project staff

CORE INDICATORS PROJECT
Pre-Survey Form: Version 2

This pre-survey form should be completed by the state or surveying organization using appropriate information sources, such as state data systems, case managers, etc. The surveyor will then use this information to schedule and conduct the interview.

Name of person completing this form: _____ **Date:** _____

CONFIDENTIAL: For State/Surveyor Use Only

Consumer's Name: _____

Phone: _____ / _____

Home address: _____
Street

City State Zip

If applicable, please answer the following:

Name of guardian: _____ **Phone:** _____ / _____

Did consumer/guardian give verbal consent for interviewer to contact him/her?

___ Yes ___ No

Was written consent obtained from consumer or guardian to be interviewed?

___ Yes ___ No *If yes, please attach copy of consent form.*

PS-1. Contact – Who should the surveyor call to arrange an interview with the this person?

Name: _____ *Phone:* _____ / _____

PS-2. Communication needs - Does this person have any special communication needs?
(Example: primary language other than English, sign language, communications board.)
Please explain what arrangements are needed for the interview:

PS-3. Service Plan - What is the annual service plan called in your organization - by what term would this person best know this document?

PS-4. Case Manager - What is the name and phone number of this person's case manager /service coordinator?

Name: _____ Phone: _____ / _____

- PS-5. **Advocate** - If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide this person's name, phone number, and relationship (Example: an advocate, guardian, personal representative, family member, friend.)

Name: _____ Phone: _____ / _____

Relationship: _____

- PS-6. **Other Interviewees** - If this person is unable or unwilling to complete Section II of the survey, please indicate the name and number of the individual(s) who could best complete that section. Besides this person, who next knows what decisions he/she makes, activities he/she does in the community, etc.?

Name: _____ Phone: _____ / _____

Relationship: _____

- PS-7. **Lives Alone/with Family/with Roommates or Housemates** - Please indicate who this person lives with.

___ lives alone ___ with parent/other relatives ___ with roommates/housemates

If applicable, provide first names of roommates or housemates:

- PS-8. **Support Staff in the Home and for Day Services** - If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several staff, please list the primary staff who spend the most time with or who have the closest relationship to this person. Also indicate the first names of any day program and/or job support staff.

Home Support Staff: _____

Day Support Staff: _____

Job Support Staff/Coach: _____

- PS-9. **Job/Day Activities** - Please indicate if this person works, attends school, or attends a day program. Please indicate the term by which he/she would be most familiar with this job, school or program.

Place of work: _____

School: _____

Day program: _____

CORE INDICATORS PROJECT Consumer Survey: Version 2

Project Background: This survey was developed in conjunction with the *Core Indicators Project*, co-sponsored by the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the project is to identify and measure *core indicators* of performance of state developmental disabilities service systems. This survey is intended to measure a subset of the performance indicators identified by the project Steering Committee.

[1.] **SURVEY CODE:** _____

(state) (unique ID number)

*Note: This code does not identify the consumer. It is for data analysis purposes only.
The first two characters should be the state 2-letter code, followed by a unique number
assigned to each consumer.*

[2.] **Region or County:** {if applicable} _____

[1.] **SURVEY CODE:** _____

(state) _____
 (unique ID number)

Note: This code does not identify the consumer. It is for data analysis purposes only.
The first two characters should be the state 2-letter code, followed by a unique number
assigned to each consumer.

[2.] **Region or County:** {if applicable} _____

[1.] **SURVEY CODE:** _____

(state) (unique ID number)

*Note: This code does not identify the consumer. It is for data analysis purposes only.
The first two characters should be the state 2-letter code, followed by a unique number
assigned to each consumer.*

[2.] **Region or County:** {if applicable} _____

BACKGROUND INFORMATION

The questions in this section are best answered by reference to agency records or computer system reference (dependent on availability by state). It is suggested that this section be completed along with the pre-survey form by the appropriate agency staff member, such as a case manager or service coordinator.

PERSONAL

[3.] Date of Birth: / /

[4.] Age: _____

[5.] Gender: male female

[6.] **Race** (*check one*): {OPTIONAL}

[6.] Race (check one): {OPTIONAL}
☐ American Indian/Eskimo/Aleut
☐ Asian/Pacific Islander
☐ Black
☐ White
☐ Other/Unknown

- [7.] **Ethnicity (*check one*): {OPTIONAL}**
☐ Hispanic
☐ Non-Hispanic
- [8.] **Legal Status:**
☐ Independent, legally competent
☐ Has private guardian (including parent/relative or non-relative)
☐ Has state or county guardian
- [9.] **Does this person have a representative payee or someone else who manages his/her money?**
☐ No
☐ Yes
☐ Unknown
- [10.] **Marital status:**
☐ Never married
☐ Married now
☐ Married in past, single now
- [11.] **Level of MR label (if any):**
☐ No MR label
☐ Mild
☐ Moderate
☐ Severe
☐ Profound
☐ Unknown or unspecified in records
- [12.] **Disabilities other than MR:**
☐ Mental illness/psychiatric diagnosis
☐ Autism
☐ Cerebral Palsy
☐ Brain injury/neurological problem
☐ Chemical dependency
☐ Other
- [13.] **Primary means of expression:**
☐ Speaks English
☐ Speaks other primary language (specify): _____
☐ Uses gestures
☐ Uses sign language or finger spelling
☐ Uses communication device

___ Other (specify): _____

[14.] Mobility:

- ___ Walks (with or without aids) or uses wheelchair
___ Non-ambulatory

[15.] Does this person use assistive devices, such as cane, walker, or wheelchair?

- ___ Yes
___ No

[16.] Does this person require mobility assistance of another person?

- ___ No, or almost never
___ Occasionally needs help of another person
___ Always requires help of another person

[17.] Vision:

- ___ Sees well, with or without corrective lenses
___ Vision problems limit activities, such as reading or travel
___ Limited or no vision (legally blind)

HEALTH

[18.] How many days in the past month (4 weeks) has this person's normal routine been interrupted because he/she was sick? [CI-41] (i.e., person did not go to work, school, day program or other scheduled activity outside the home due to being sick)

___ ___ Number of days

[19.] Does this person currently take medications for...

- | | | |
|---|---------|--------|
| Mood, Anxiety, Sleep, or Behavior problems? | ___ Yes | ___ No |
| Epilepsy or Seizures? | ___ Yes | ___ No |
| Other health problems? | ___ Yes | ___ No |

[20.] If this person has seizures, about how often do they occur?

- ___ N/A -- does not have seizures, or seizures are controlled
___ Less than once/month
___ Once/month
___ Once/week
___ More than once/week

[21.] **About how often does this person require professional medical care?**

- ☐ Less than once/month
- ☐ Once/month
- ☐ Once/week
- ☐ Once/day
- ☐ Requires 24-hour immediate access to medical care

[22.] **When was his/her last physical exam?** [CI-42]

___/___

[23.] **If female, when was her last OB/GYN exam?** [CI-43]

___/___

[24.] **When was his/her last dental check-up?** [CI-45]

___/___

RESIDENCE

[25.] **How many different places has this person lived within the past year?** (*Count one for present home. Do not include moves within the same facility.*) [CI-57]

___ Number of places

[26.] **How would you characterize the place where this person lives?**

- ☐ 1 Specialized facility for persons with MR/DD (includes ICFs/MR)
- ☐ 2 Group home
- ☐ 3 Apartment program (**agency** owns or leases the apartment)
- ☐ 4 Independent home or apartment (agency may provide support, but **person** owns or leases the home)
- ☐ 5 Parent/relative's home
- ☐ 6 Foster care or host home (person lives in home of unrelated, paid caregiver)
- ☐ 7 Nursing facility
- ☐ 8 Other (specify) _____

[27.] **Who owns or leases the place where this person lives?**

- ☐ 1 Family, guardian, or friend
- ☐ 2 Private agency
- ☐ 3 State or County agency
- ☐ 4 Person rents home (name is on the lease)
- ☐ 5 Person owns home (name is on the title)

- ☐ 6 Don't know
☐ 7 Other

[28.] How many people live in the residence?

- ☐ ☐ number of people with developmental disabilities (including person receiving services)
☐ ☐ number of people without developmental disabilities

[29.] What amount of residential support does this person receive?

- ☐ 1 24-hour on-site support or supervision
☐ 2 Daily on-site support for a limited number of hours/day
☐ 3 Less frequent than daily support
☐ 4 None of the above

[30.] Location of residence:

- ☐ 1 Physically remote; not within walking distance to city/town or to public transportation
☐ 2 Within walking distance to city/town or to public transportation
☐ 3 Centrally located within the city or town

OTHER SUPPORTS AND SERVICES

[31.] Does this person receive Home and Community Based Waiver Services?

- ☐ Yes
☐ No
☐ Don't know

[32.] Other supports person is currently receiving (check one column for each):

<i>yes</i>	<i>no</i>	<i>don't know</i>	
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Service Coordination / Case Management
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vocational – supported employment
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vocational – group employment (enclave, mobile crews)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Vocational – facility based (sheltered workshops, work activity centers)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Non-vocational day service – facility based (day habilitation, day treatment, seniors programs)
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	Community participation/accessibility connections (supports

used to get people into the community)

—	—	—	Assistive technology (supports to facilitate the use of adaptive equipment)
—	—	—	Clinical Services (therapies, behavior management, psychological services, etc.)
—	—	—	Transportation
—	—	—	Respite

FREQUENCY OF PROBLEM BEHAVIOR

For each of the types of behavior described, please indicate whether or not this person exhibits this behavior, and if so, about how often.

- [33.] **Self-Injury:** Does this person ever cause injury to him/herself, for example, by hitting self, biting, banging head, scratching or puncturing skin?

☐ No ☐ Yes

If yes, about how often does the behavior occur?

- ☐ once/month
☐ 1-3 times/month
☐ 1-6 times/week
☐ 1-10 times/day
☐ one or more times/hour

- [34.] **Property Destruction:** Does this person ever deliberately break, deface, or destroy things, for example, by tearing or cutting, throwing, or burning things?

☐ No ☐ Yes

If yes, about how often does the behavior occur?

- ☐ once/month
☐ 1-3 times/month
☐ 1-6 times/week
☐ 1-10 times/day
☐ one or more times/hour

- [35.] **Disruptive Behavior:** Does this person ever interfere with the activities of others, for example, by starting fights, laughing or crying without reason, yelling or screaming?

☐ No ☐ Yes

If yes, about how often does the behavior occur?

- ☐ once/month
☐ 1-3 times/month
☐ 1-6 times/week
☐ 1-10 times/day
☐ one or more times/hour

- [36.] **Uncooperative Behavior:** Does this person ever engage in "uncooperative" behavior, for example, breaking rules or laws, cheating, acting defiant, or stealing?

☐ No ☐ Yes

If yes, about how often does the behavior occur?

- ☐ once/month
☐ 1-3 times/month
☐ 1-6 times/week
☐ 1-10 times/day
☐ one or more times/hour

SECTION I: Direct Interview with Person Receiving Services

Instructions to the Surveyors:

This section may only be completed by **direct interview with the person receiving services**. Do not use responses from any other person to complete this section. Consumers may skip any question. If the person receiving services does not respond to a question or gives an unclear response, code the question as "9." Do not leave any questions blank.

Take a few minutes to introduce yourself and make the person feel comfortable. Then read or paraphrase the following introduction to the person receiving services. Pause after each statement, making sure the respondent understands.

- Thank you for letting us come and talk with you today. We are interviewing people in many states across the country to try to learn how to help people better. I am going to ask you several questions about your where you live, where you work, your friends and family, and the people who help you.
- This is not a test. There are no right or wrong answers to these questions. If you don't understand a question, let me know and I will try to explain it. It's okay if you don't know how to answer.
- You do not have to answer any questions that you don't want to. Just tell us if you do not want to answer.
- We would like to know your opinions, how you feel about things. Please tell us how you honestly feel. We will not share your answers with anyone unless you ask us to.

(If applicable): Ask respondent to sign consent form before proceeding with interview.

WORK/SCHOOL

Prompt: First, I'd like to ask you about what you do during the day.

[1.] Do you usually go somewhere during the day?

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear response

If yes, prompt: Where do you usually go? [verify job, school, day activity with PS-9]

[2.] Do you like what you do there? [CI-17]

☐ 8 N/A – no job, school, or day program

- ☐ 2 Yes
- ☐ 1 In-between
- ☐ 0 No
- ☐ 9 No response, unclear response

Prompt: Do you have staff who help you there? [refer to names listed in PS-8]

[3.] Are the people who help you there nice and polite to you? [CI-53] (Surveyor - we are trying to determine whether or not staff are sensitive to this person's disability.)

- ☐ 2 Yes, most staff, most times
- ☐ 1 Sometimes, some staff
- ☐ 0 No, some staff often are not nice
- ☐ 8 N/A, no work or day support staff
- ☐ 9 No response, unclear response

If this person has a job, ask:

[4.] Are you happy with the hours you work, or would you like to work more?
[CI-18]

☐ 8 N/A – does not have a job

- ☐ 2 Yes, work as much as I'd like to
- ☐ 0 No, would like to work more hours
- ☐ 9 No response, unclear response

[5.] Do you usually stay home all day? [CI-consistency]

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear response

FRIENDS AND FAMILY

Prompt: Next, I'd like to ask you about your friends and family...

[6.] Do you have friends you like to talk to or do things with? [CI-12] *(Surveyor - if he/she answers 'yes,' ask who the friends are and try to determine if they are family, staff, roommates, co-workers, etc. You can use prompts such as: Can you tell me their names? Are these friends staff or your family? Can you think of other friends you could tell me about?)*

- ☐ 2 Yes - has friends who are not staff or family
- ☐ 1 Yes - friends are all staff or family, or not sure whether they are staff/family or not
- ☐ 0 No
- ☐ 9 No response, unclear response

[7.] Do you have any best friends? [CI-13] *(Is there someone you can talk to about personal things?) (Surveyor - It doesn't matter if they are family or staff here.)*

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear response

[8.] Do you ever feel lonely, like you don't have any friends to talk to? [CI-15] *(Surveyor - if he/she responds "yes," probe to determine how often he/she feels lonely.)*

- ☐ 2 Never feel lonely
- ☐ 1 Sometimes, a few times, rarely felt lonely
- ☐ 0 Always or often felt lonely
- ☐ 9 No response, unclear response

- [9.] **Can you see your friends when you want to see them?** [CI-14a] *(Surveyor – we are trying to determine if there are restrictions on when he/she can see friends – i.e., can he/she pick the times, are travel arrangements made when he/she wants to see friends. Try to factor out situations where the friend themselves are not available – this is not the issue.)*

☐ 8 N/A – don't have any friends

- ☐ 2 Yes, can see them when I want to
☐ 1 Sometimes
☐ 0 No
☐ 9 No response, unclear response

- [10.] **Do you have family that you see?**

- ☐ 2 Yes
☐ 0 No
☐ 9 No response, unclear response

Surveyor: If person has family but does not want to see them, code the following question as "2" and do not read the question. If family is not available, code the question as "N/A."

- [11.] **Can you see your family when you want to?** [CI-14b] *(Can you pick the times you see them? Does someone help you make plans to see them?)*

- ☐ 2 Yes, can see them when I want to, or choose not to see family
☐ 1 Sometimes
☐ 0 No
☐ 8 N/A – family not available , or person lives with family
☐ 9 No response, unclear response

HOME

Prompt: Next, I'd like to ask a few questions about where you live.

[12.] Do you like where you live? [CI-16] *(Do you like living here?)*

- ☐ 2 Yes
- ☐ 1 In-between
- ☐ 0 No
- ☐ 9 No response, unclear response

[13.] Are you usually happy living here or sad living here? [CI-consistency]

- ☐ 2 Happy
- ☐ 0 Sad
- ☐ 9 No response, unclear response

[14.] Can you be alone as much as you want to? [CI-49] *(Do you have enough times when you can be alone?)*

- ☐ 2 Yes, has enough time alone
- ☐ 0 No, wish I had more time alone
- ☐ 9 No response, unclear response

[15.] Do you feel safe and comfortable where you live? [CI-40b]

- ☐ 2 Yes, feel safe there
- ☐ 1 In-between
- ☐ 0 No, don't feel safe
- ☐ 9 No response, unclear response

[16.] When you go outside your home, do you ever feel scared or do you always feel safe? [CI-40a] *(Do you feel safe in your neighborhood? Do you ever feel afraid to go outside for a walk?)*

- ☐ 2 Feel safe
- ☐ 1 In-between
- ☐ 0 Feel scared
- ☐ 9 No response, unclear response

[17.] Are you usually sad living here or happy living here? [CI-consistency]

- ☐ 2 Good
- ☐ 0 Bad
- ☐ 9 No response, unclear response

Prompt: Do you have staff who help you where you live? *[refer to names listed in PS-8]*

[18.] Are the people who help you where you live nice and polite to you? [CI-53]

- ☐ 2 Yes, most staff, most times
- ☐ 1 Sometimes, some staff
- ☐ 0 No, some staff often are not nice
- ☐ 8 N/A, no home support staff
- ☐ 9 No response, unclear response

[19.] Do you wish you had more time alone?

- ☐ 2 No, have enough time alone
- ☐ 0 Yes, wish I had more time alone
- ☐ 9 No response, unclear response

SERVICES/SUPPORTS COORDINATION

Prompt: Do you have a case manager [or service coordinator]? What is your case manager's name? _____ *[verify with PS-4]*

[20.] Can you talk to _____ *[enter name of service coordinator, case manager, or caseworker – see pre-survey PS-4]* when you want to? [CI-21]

- ☐ 2 Yes
- ☐ 0 No, or only sometimes, or does not know case manager
- ☐ 8 N/A, doesn't have a case manager
- ☐ 9 No response, unclear response

Prompt: Do you have an advocate or a guardian, someone who speaks up for you and helps you make decisions? What is your that person's name?

_____ *[verify with PS-5]*

- ☐ 2 Yes, knows advocate's name
- ☐ 1 Maybe, not sure - does not know advocate's name
- ☐ 0 No

☐9 No response, unclear response

[21.] Can you talk to him/her when you want to? [CI-21]

- ☐2 Yes
- ☐0 No, or only sometimes
- ☐8 N/A, doesn't have an advocate
- ☐9 No response, unclear response

[22.] When you want to talk to your case manager, is it hard to get in touch with him/her?

- ☐2 No, or only sometimes
- ☐0 Yes
- ☐8 N/A, doesn't have a case manager
- ☐9 No response, unclear response

Prompt: **Did you have a _____** *[Please substitute the word used in your state for service plan – see pre-survey PS-3]* **meeting this year?** *[If no, code the following three questions as "N/A." If yes, continue:]*

[23.] At the meeting, did people listen to what you had to say? [CI-22]

- ☐2 Yes
- ☐1 Sometimes
- ☐0 No
- ☐8 N/A, did not have an annual meeting
- ☐9 No response, unclear response

[24.] Did you choose the things that are in your _____ *[Please substitute the word used in your state for service plan – see pre-survey PS-3]* **? [CI-22]**

- ☐2 Yes
- ☐1 Some, a few
- ☐0 No
- ☐8 N/A, doesn't have a plan
- ☐9 No response, unclear response

[25.] Do you think these things are important or not important? [CI-8]

- ☐ 2 Important
- ☐ 1 In-between
- ☐ 0 Not important
- ☐ 8 N/A, doesn't have a plan
- ☐ 9 No response, unclear response

[26.] What new things did you get help to learn this year? [CI-19] *(Are you able to do more things independently this year?)*

- ☐ 1 Learned some new things this year
- ☐ 0 Did not learn anything new this year
- ☐ 9 No response, unclear response

[27.] Could Section I be completed?

- ☐ 1 Yes, the person receiving services answered the questions independently
- ☐ 2 Yes, the person receiving services answered the questions with someone else's assistance
- ☐ 3 No, person could not communicate sufficiently to complete this section
- ☐ 4 No, person was unwilling to participate
- ☐ 5 No, was unable to schedule interview or other reason, explain _____

SECTION II: Interview with the Person Receiving Services or Other Respondents

Instructions to Surveyor: Interview the person receiving services if possible. If you are unable to interview the person, other respondents may be interviewed (family, advocate, staff) if they are knowledgeable in the areas below. If the person receiving services has completed Section I, but has become tired or does not wish to continue with this section, you may interview other persons.

Ask the person if he/she wishes to continue with the survey.

COMMUNITY INCLUSION

[28.] Do you [does this person] go shopping? *[If necessary, give examples: for groceries, clothing, housewares, tapes/CDs.]* [CI-6a]

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear, don't know

[29.] Do you [does this person] go out on errands or appointments? *[If necessary, give examples: doctor, dentist, bank, post office, hair dressers/barber.]* [CI-6b]

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear, don't know

[30.] Do you [does this person] go out to exercise or play sports? *[If necessary, give examples: walking, hiking, jogging, skating, biking, fishing, bowling, golfing, swimming.]* [CI-6c]

(Note to surveyor – please be sensitive to person's level of mobility when listing these items. If this person participates only in non-integrated sports activities (e.g. Special Olympics), the response should be coded as "No.")

- ☐ 2 Yes
- ☐ 0 No
- ☐ 9 No response, unclear, don't know

[31.] Do you [does this person] go out for entertainment? *[If necessary, give examples: movies, library, plays, concerts, museums, art galleries.]* [CI-6d]

- ☐ 2 Yes
☐ 0 No
☐ 9 No response, unclear, don't know

[32.] Do you [does this person] go out to eat at restaurants? [CI-6e]

- ☐ 2 Yes
☐ 0 No
☐ 9 No response, unclear, don't know

[33.] Do you [does this person] go to religious services or events? [If necessary, give examples: church, synagogue.] [CI-6f]

- ☐ 2 Yes
☐ 0 No
☐ 9 No response, unclear, don't know

[34.] Have you [has this person] ever participated in a self-advocacy group meeting, conference, or event? [For example, People First, Speaking for Ourselves, Arc, Legal Center, etc.] [CI-48]

- ☐ 2 Yes
☐ 0 No
☐ 9 No response, unclear response, don't know

CHOICES

Note to surveyor: In this section, code "yes" only if you can convince yourself that this person made a real choice. Choices made with spouses/partners are considered "unassisted."

[35.] Did you choose or pick the place where you live? [CI-7a] (Surveyor – see PS-7 to find out if he/she lives with parents/relatives. Did you look at other places before moving here?)

(Other respondent – Did this person choose the place where he/she lives?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me
☐ 8 N/A, live in parent/relative's home (See PS-7)
☐ 9 No response, unclear response, can't remember – too long ago

- [36.] **Did you choose or pick what you did today, or what you are going to do this week (such as when to eat, clean house, or do laundry)?** [CI-7c] *(Do you decide what time of day you should bathe, eat your meals? Who decides when in the week you should do laundry, clean house, or other tasks that occur weekly?)*

(Other respondent – Does this person choose his/her daily and weekly schedule, such as when to eat, clean house, or do laundry?)

- ☐ 2 Yes, unassisted
- ☐ 1 Yes, with assistance
- ☐ 0 No, someone else chooses for me
- ☐ 9 No response, unclear response, can't remember – too long ago

- [37.] **Did you choose or pick the people you live with?** [CI-7b] *(Did anyone ask you who you'd like to live with? If so, did you get to live with the people you said you'd like to live with? Were you given choices, did you get to interview people? Surveyor – if you need to, you can use the names of their roommates here from PS-7)*

(Other respondent – Did this person choose the people he/she lives with?)

- ☐ 2 Yes, unassisted
- ☐ 1 Yes, with assistance or some of the roommates
- ☐ 0 No, someone else chose the people I live with
- ☐ 8 N/A – lives at home with parents or other relatives (See PS-7), or lives alone
- ☐ 9 No response, unclear response

- [38.] **Did you choose or pick _____** *[insert first name of paid staff or agency who provides supports within their home, if any – see pre-survey PS -8]* **to help you at home?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people or agencies and help pick one?)*

(Other respondent – Did this person choose or hire staff or agencies to help him/her at home?)

- ☐ 2 Yes, unassisted
- ☐ 1 Yes, with assistance or some staff
- ☐ 0 No, someone else chose for me

- ☐ 8 N/A, no support staff in the home (see PS-8)
☐ 9 No response, unclear response

[39.] Did you choose or pick _____ *[insert first name of paid staff who provide supports at work or day program from PS-8 and reference work/day program as is relevant per PS-9]* **to help you at your job?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)*
(Other respondent – Did this person choose or hire staff at work or at their day program?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me
☐ 8 N/A, no support staff for day program/work (see PS-8)
☐ 9 No response, unclear response

[40.] Did you choose to work at _____ [CI-7new] *[reference job as is relevant per PS-9]? (Did you look at more than one job?)*
(Other respondent – Did this person choose his/her job?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me
☐ 8 N/A, does not go to day program or work (see PS-9)
☐ 9 No response, unclear response

[41.] Did you choose or pick _____ *[insert first name of paid staff who provide supports at work or day program from PS-8 and reference work/day program as is relevant per PS-9]* **to help you at your day program?** [CI-7d] *(Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)*
(Other respondent – Did this person choose or hire staff at work or at their day program?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me

- ☐ 8 N/A, no support staff for day program/work (see PS-8)
☐ 9 No response, unclear response

[42.] Did you choose to go to _____ [CI-7new] [reference day program as is relevant per PS-9]? (Did you look at more than one day program?)
(Other respondent – Did this person choose their work or day program?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me
☐ 8 N/A, does not go to day program or work (see PS-9)
☐ 9 No response, unclear response

[43.] Did you choose or pick _____ [insert first name of service coordinator/case manager from PS-4] to help you get what you need? [CI-7d] (Did anyone ask you about hiring them? Did you get to talk to several possible people and help pick one?)
(Other respondent – Did this person choose or hire his/her service coordinator?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chose for me
☐ 8 N/A, no case manager (see PS-8)
☐ 9 No response, unclear response

[44.] Do you choose or pick the things you do for fun? [CI-7e] (Do you choose how you spend your evenings, weekends, or time off from work, school, or day program? Who chooses what activity to do and where you do it? Ex: Whether to take a walk, play a game, watch TV, select what's on TV, etc.)
(Other respondent – Does this person choose the things he/she does for fun?)

- ☐ 2 Yes, unassisted
☐ 1 Yes, with assistance
☐ 0 No, someone else chooses for me
☐ 9 No response, unclear response

Prompt: Do you have someone who helps you with your money?

[45.] When you want some of your money, does [name of representative payee] help you get it? [CI-11a] (Surveyor – we are trying to determine if this person accesses his/her money at will. We are not looking at this person's skill level.)
(Other respondent – Can this person have his/her own money whenever he/she wants it?)

- ☐_2 Yes, can get my money when I want it
- ☐_0 No, can not get my money when I want it
- ☐_9 No response, unclear response
- ☐_8 N/A, does not have a representative payee

[46.] Do you choose the things you buy with your own money?

[CI-11b] *(Surveyor – give examples, do you pick how to spend your money on things that are important to you, like games, clothes, music, movies, etc.? We are asking about spending money only; do not include groceries/food shopping.)*

(Other respondent – Does this person choose the things he/she wants to buy, or does someone else choose what he/she buys?)

- ☐_2 Yes, unassisted
- ☐_1 Yes, with assistance
- ☐_0 No, someone else chose for me
- ☐_9 No response, unclear response

RIGHTS

[47.] When you get mail, who opens it? [Surveyor: Probe to find out if this person opens all mail addressed directly to him/her. Do you open letters or birthday cards? Do you open bills? If someone other than this person opens his/her mail, ask:] Did you tell that person it was okay to open your mail? [CI-47b]

(Other respondent – Does anyone ever open this person's mail without permission?)

- ☐_2 No, his/her mail is not opened without his/her permission
- ☐_1 Yes, some mail is opened without his/her permission
- ☐_0 Yes, always opened without his/her permission
- ☐_9 No response, unclear response

[48.] When you have guests over, can you be alone with them, or does someone

have to be with you? [CI-47c]

(Other respondent – can this person have privacy to be alone with guests when he/she wants to, or does someone else have to be present? Can he/she have overnight guests?)

- ☐_2 Can have privacy with guests
- ☐_1 Not always - there are some restrictions (e.g. can't have overnight guests)
- ☐_0 Can not be alone with guests - must always have someone present
- ☐_9 No response, unclear response

[49.] Does anyone come into your home without asking? [CI-47d] *(Excluding other people who also live in the home. We are talking about staff, case managers, landlords, etc. Do they ring the doorbell or knock first and wait for you to answer?)*

(Other respondent – Does anyone enter this person's home without permission?)

- ☐_2 No, no one enters the house without permission
- ☐_0 Yes, people not living there do enter the house without permission
- ☐_9 No response, unclear response

[50.] Does anyone come into your bedroom without asking?

(Other respondent – Does anyone enter this person's bedroom without permission?)

- ☐_2 No, no one enters this person's bedroom without permission
- ☐_0 Yes, people not living there do enter this person's bedroom without permission
- ☐_9 No response, unclear response

[51.] Are you allowed to use the phone when you want to? [CI-47e]

(Other respondent – are there any restrictions on his/her use of the telephone?)

- ☐_2 No, there are no restrictions, can use anytime, either independently or with assistance
- ☐_0 Yes, there are some restrictions, or person is not allowed to use or have a phone
- ☐_8 N/A doesn't have phone or unable to use phone
- ☐_9 No response, unclear response

ACCESS

- [52.] Can you think of anything you asked for help with but didn't get? (Give examples of services and supports, such as transportation, job coaching, in-home support, education, clinical services, etc.) [CI-30]

(Other respondent – Are there services or supports that this person needed that he/she couldn't get in the past year?)

- ☐ 2 No
☐ 0 Yes
☐ 9 No response, unclear response

- [53.] When you want to go somewhere, do you always have a way to get there or not? [CI-20]

(Other respondent – When this person wants to go somewhere, does he/she have a way to get there?)

- ☐ 2 Almost always
☐ 1 Sometimes
☐ 0 Almost never
☐ 9 No response, unclear response

- [54.] Are staff able to understand what you want? [CI-61] (Surveyor – see PS-2. This question primarily applies to individuals who do not use spoken English as their primary way of communicating. For example, if this persons speaks Spanish, then do most staff interacting with him or her speak Spanish? If this persons uses sign language, then do most staff interacting with him/her know sign language?)

(Other respondent – Are staff able to communicate with this person?)

- ☐ 2 Yes, most times and most staff and understand me
☐ 1 Some staff, sometimes
☐ 0 No, few or no staff, rarely
☒ 8 N/A, spoken English is primary communication mode
☐ 9 No response, unclear response

- [55.] (Surveyor - refer to PS-2. If this person uses an interpreter or communication device, ask the following questions:) Do you have an interpreter whenever you need one?

[if applicable] **Do you know how to use your communication board?** [CI-10a]

(Other respondent – Does this person have communication devices, hearing aids, interpreters, or other things he/she needs in order to communicate?)

- ☐ 2 Yes, has complete access and knows how to use
- ☐ 1 Yes, has limited access, needs more devices or needs to better understand use, or needs assistance and does not always have someone available to assist
- ☐ 0 No access
- ☐ 8 N/A- none needed
- ☐ 9 No response, unclear response

[56.] Do you use any special equipment to get around, such as a hearing aid, a wheelchair, etc.? [CI-10b] *(Surveyor - refer to PS-10, verify if this person has and knows how to use the equipment listed.)*

(Other respondent – Does this person have adaptive equipment if needed, such as walkers, wheelchairs, braces/splints, etc.?)

- ☐ 2 Yes, has complete access and knows how to use
- ☐ 1 Yes, has limited access, needs more devices or needs to better understand use, or needs assistance and does not always have someone available to assist
- ☐ 0 No access
- ☐ 8 N/A- none needed
- ☐ 9 No response, unclear response

[57.] Please indicate who completed this section:

- ☐ 1 Person receiving services
- ☐ 2 Advocate, Parent, Guardian, Personal Representative, Relative
- ☐ 3 Staff who provides supports where person lives
- ☐ 4 Staff who provides supports at a day or other service location
- ☐ 5 Case Manager, service coordinator, social worker, resource coordinator
- ☐ 6 Other, Specify _____

Note to Surveyor:

If the person receiving services did not complete this section, please indicate the last question he/she responded to. Question number: _____

If someone else finished answering the questions in this section, please indicate that person's name and relationship to the person receiving services.

Name: _____

Relationship: _____

SECTION III: Interview with Advocate, Guardian, or Personal Representative who can respond to questions concerning Services/Supports Coordination

Instructions to Surveyors:

If the person receiving services was able to complete Section I, then the survey is complete. The surveyor should code all questions in Section III as "N/A."

If this person was unable to respond to Section I, ask an advocate, guardian, or personal representative to answer the questions in Section III. Do not ask staff or providers to answer questions in Section III. If no advocate, guardian, or personal representative is available, code all questions in Section III as "9."

Prompt: Does the person you represent have a case manager? What is the case manager's name? _____ *[verify with PS-4]*

[20a.] Can you talk to _____ *[enter name of service coordinator, case manager, or caseworker – see pre-survey PS-4]* **when you want to?** [CI-21]

- ☐ 2 Yes
- ☐ 0 No, or only sometimes, or does not know case manager
- ☐ 8 N/A, doesn't have a case manager

Prompt: Did the person you represent have a _____ *[Please substitute the word used in your state for service plan – see pre-survey PS-3]* **meeting this year?** *[If no, code the following three questions as "N/A." If yes, continue:]*

[23a.] At the meeting, did people listen to what you and the person you represent had to say? [CI-22]

- ☐ 2 Yes
- ☐ 1 Sometimes
- ☐ 0 No
- ☐ 8 N/A

[24a.] Did you and the person you represent choose the things that are in his/her _____ *[Please substitute the word used in your state for service plan – see pre-survey PS-3]* **?** [CI-22]

- ☐ 2 Yes
- ☐ 1 Some, a few

- ☐ 0 No
- ☐ 8 N/A, doesn't have a plan

[25a.] Do you think these things are important to the person you represent? [CI-8]

- ☐ 2 Yes
- ☐ 1 Some, a few
- ☐ 0 No
- ☐ 8 N/A, doesn't have a plan

[26a.] What new things did the person you represent get support to learn this year? [CI-19]

- ☐ 1 Learned some new things this year
- ☐ 0 Did not learn anything new this year

[27a.] Please indicate who respondent to this section.

- ☐ 1 Advocate
- ☐ 2 Guardian
- ☐ 3 Personal representative/friend
- ☐ 4 Section could not be completed - no respondent available

SURVEYOR FEEDBACK SHEET

Instructions to interviewers:

Please take a few minutes to complete a feedback sheet after each interview you complete.

Interviewer's Initials: _____

1. Was this interview conducted in person, by telephone, or both?
A. ☐ In-person B. ☐ Telephone C. ☐ Both
2. Were there any questions that were unclear or difficult to explain to the subject?
☐ No ☐ Yes, list question numbers here: _____
3. How long did it take to complete the interview?
☐ Minutes
4. Were there any questions that elicited an emotional response from the subject?
☐ No ☐ Yes, list question numbers here: _____
5. Were there any questions that were problematic in any way?
☐ No ☐ Yes, please describe below.

Question #:

Problem:

[illegible]

Name: _____ Phone: _____ / _____

- PS-5. **Advocate** - If this person has someone who helps represent him/her at planning meetings and in making important decisions, please provide this person's name, phone number, and relationship (Example: an advocate, guardian, personal representative, family member, friend.)

Name: _____ Phone: _____ / _____

Relationship: _____

- PS-6. **Other Interviewees** - If this person is unable or unwilling to complete Section II of the survey, please indicate the name and number of the individual(s) who could best complete that section. Besides this person, who next knows what decisions he/she makes, activities he/she does in the community, etc.?

Name: _____ Phone: _____ / _____

Relationship: _____

- PS-7. **Lives Alone/with Family/with Roommates or Housemates** - Please indicate who this person lives with.

____ lives alone ____ with parent/other relatives ____ with roommates/housemates

If applicable, provide first names of roommates or housemates:

- PS-8. **Support Staff in the Home and for Day Services** - If there are any people who are paid to provide supports in this person's home, please indicate their first names. If there are several staff, please list the primary staff who spend the most time with or who have the closest relationship to this person. Also indicate the first names of any day program and/or job support staff.

Home Support Staff: _____

Day Support Staff: _____

Job Support Staff/Coach: _____

- PS-9. **Job/Day Activities** - Please indicate if this person works, attends school, or attends a day program. Please indicate the term by which he/she would be most familiar with this job, school or program.

Place of work: _____

School: _____

Day program: _____

Core Indicators Project – Family Survey

Please provide the following information about your family. All responses will be kept **strictly confidential**.

- a. In what county/region does your family live? _____ (if applicable)
- b. What is your relationship to your family member with a disability?
☐ Parent (natural or adoptive)
☐ Sibling or other relative
☐ Other (specify) _____
- c. What is your family's race?
☐ American Indian/Eskimo/Aleut
☐ Asian/Pacific Islander
☐ Black
☐ White
☐ Other/Unknown _____
- d. What is your family's ethnicity?
☐ Hispanic
☐ Non-Hispanic
- e. What is the age of the primary caregiver? _____
- f. What is the health status of the primary caregiver?
☐ Excellent
☐ Average
☐ Poor
- g. What is the age of the individual with a disability? _____ ☐ Don't know
- h. Are you on a waiting list for services?..... ☐ Yes ☐ No ☐ Don't know
- i. Does your family receive:
Case management/service coordination..... ☐ Yes ☐ No ☐ Don't know
Family Support..... ☐ Yes ☐ No ☐ Don't know
Other services/supports (specify) _____
- j. Does your family member receive:
Case management..... ☐ Yes ☐ No ☐ Don't know
In-home supports..... ☐ Yes ☐ No ☐ Don't know
Vocational services..... ☐ Yes ☐ No ☐ Don't know
Transportation..... ☐ Yes ☐ No ☐ Don't know
Other services/supports (specify) _____

Core Indicators Project – Family Survey

INFORMATION

	Most of the time N/A	Some of the time	Rarely	Don't Know	
1. Do you receive information about services and supports that are available to your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the information easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CHOICE/PLANNING

	Most of the time N/A	Some of the time	Rarely	Don't Know	
3. Do you choose who helps you, such as your service coordinator, case manager, or home support provider?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is turnover of staff that work with you a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do the staff work together with you to identify what you need as a family to support your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do they present you and your family member with a range of options to meet your needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do they respect your choices and preferences?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ACCESS

	Most of the time N/A	Some of the time	Rarely	Don't Know	
8. Do the supports offered reflect the needs of your <i>family</i> as well as your family member with a disability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is your family getting the supports you need, such as respite care, training, or education?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Are supports available when your family wants and needs them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. In a crisis, are supports available in a timely manner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do staff communicate with you in your preferred language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

LINKAGES

	Most of the time N/A	Some of the time	Rarely	Don't Know	
13. Do the staff help you get other supports in your community, such as services offered through vocational rehabilitation programs, recreation departments, churches, or medical services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Core Indicators Project – Family Survey

14. Do the staff help you find family, friends, or neighbors who can provide some of the supports your family needs?

☐ ☐ ☐ ☐ ☐

Please use the space below for any other comments you would like to make.

Please note: It is our policy to keep all responses to this survey anonymous and confidential. However, if you have a specific concern that needs to be addressed and you would like someone to contact you, **please check here to waive confidentiality:** ☐

What is the best way to contact you? _____

>>> DRAFT <<<

4/26/99

FAMILY SURVEY II

This is a second family survey that will be administered to guardians or families of adults who are receiving services and do not live at home.

The following proposed questions are taken from the Kansas Community Integration Project (also known as CIP) Guardian Survey:

- a. How would you rate the adequacy of information provided to you to help you participate in the person-centered plan process for the services your son/daughter/ward currently receives?
- b. How would you rate the effort of the agency providing residential services to your son/daughter/ward to involve you in important decisions (for example, medical, dental, where to live, roommate)?
- c. How would you rate the effort of the agency providing day services to your son/daughter/ward to involve you in important decisions (for example, where to work)?
- d. How would you rate how healthy and safe your son/daughter/ward is in his/her living arrangement?
- e. How would you rate how healthy and safe your son/daughter/ward is in his/her day services arrangement?
- f. How would you rate the level of involvement your son/daughter/ward has in community activities he/she/you value?
- g. How would you rate the overall services and supports your son/daughter/ward is receiving now?
- h. How would you rate the happiness of your son/daughter/ward in his or her current situation?

All ratings would be made using a 1-5 Likert scale.

Outstanding issues regarding the family survey(s):

- Should this survey be integrated with the Family Support Survey from last year? Can we do this without losing the focus of the family support survey? Will it get too long to fill out?
- How do we handle situations where the family is not involved because the consumer wants it that way? If we begin by selecting "guardians," will that work? Should we include other types of advocates, friends, etc.?

- Additional questions on Natural Supports may be added to either or both family surveys, such as "Does the person participate in activities that do not require the involvement of the DD agency?"
- Additional probes may be added regarding supports provided by the DD agency when a family is in crisis and requests assistance.

>>> DRAFT <<<

4/26/99

CIP PROVIDER SURVEY

I. Employment Indicators

- To be filled out by all providers who receive "day support" funding.
- Employment information should be reported by category of support (**duplicated counts**).
- The total number of people receiving day supports (**unduplicated count**) should be reported at the bottom.

	CATEGORY OF DAY SUPPORT				
INDICATOR	Group Facility- Based (sheltered work)	Individual Supported Employment	Group SEP (enclave, work crew)	Other??? (volunteer activities, etc.)	
a. Average monthly wage.					
b. Average number of hours worked per month.					
c. Percent earning at or above the state minimum wage (\$?.??).					
d. Average number of months in <i>continuous</i> employment (not necessarily at same job).					
Subtotals by category of support (duplicated)					
Total number of persons served (unduplicated)					

Outstanding issues concerning employment indicators:

- Are monthly figures the way to go? If yes, should they be reported for a specific month, or an average monthly figure for the year?
- Should vocational/day supports provided outside of the DD agency be included? (e.g. VR contracted providers)
- What other categories of day supports should we include, if any?
- Should the survey go to all providers or to a sample of providers?

Note: An optional, parallel set of questions will be adapted for the consumer survey, for those states that wish to collect this information on an individual level.

II. WORKFORCE TURNOVER

- Data on direct contact staff turnover will be broken down into two categories: (1) "Traditional" Day and Residential Services and (2) "Non-traditional" Supports.

Providers that fall into the first category will be asked to provide the following information:

- a. For workers who have left the agency (resigned or terminated) in the past year, a list of dates of hire and departure.
- b. The number of direct contact positions (full and part time), as of June 30, 1999.
- c. The number of filled and vacant direct contact positions, as of June 30, 1999.
- d. Overtime payroll costs for the past year (if applicable).
- e. For currently employed staff, a list of their dates of hire.

Outstanding issues concerning turnover indicators:

- Measures and protocols for collecting this information from "Non-traditional" providers need to be developed.

III. Data from Incident Reports

The following indicators are generally reported in incident reports, and may be included on the provider survey:

- a. The number of serious injuries reported in the past year.
- b. The proportion of people who were victims of crimes reported to a law enforcement agency during the past year.
- c. Number of deaths reported in the past year.
- d. The total number of people for whom the provider is required to report unusual incidents. (This may or may not be the entire service population.)

IV. Financial Ratios

If the information is not available at the state level, providers will either be asked to submit financial statements, or the following figures:

- Current and Total Assets
- Current and Total Liabilities
- Net Worth
- Revenues from Private Sources
- Total Revenues
- Total Salaries and Wages
- Total Expenditures
- Accumulated Depreciation

In addition, agencies will be asked to provide the following descriptive information:

- Profit/nonprofit status
- Whether the agency or parent agency operates in more than one state
- Types of services and supports provided
- Populations served
- Whether or not the agency is responsible for administering the system of services in a certain region of the state in addition to providing direct services and supports.

V. Other Indicators

Other measures that may be requested on the provider survey include:

- a. Number of individuals served by race and ethnicity (using census categories).
- b. Number of consumers and family members on provider board of directors and/or program committees, and total number of board/committee members.

Topics to Think About...

- Medications/ medical issues
- Health/ safety/ licensing violations
- Access
- Value of money (cost-effective)
- Individual protections
- Direct support workforce
- Choices/ empowerment / quality of life
- Staff training
-
-

Most consumers have no idea what the costs are

1. What questions do we need to ask?
2. What things/ items do we need to review or look at?
3. Who would it be important for us to solicit information from?
4. What are the most critical issues for us to evaluate?

Core Indicators Project – Family Survey

Please provide the following information about your family. All responses will be kept **strictly confidential**.

- a. In what county/region does your family live? _____ (if applicable)
- b. What is your relationship to your family member with a disability?
- ☐ Parent (natural or adoptive)
 - ☐ Sibling or other relative
 - ☐ Other (specify) _____
- c. What is your family's race?
- ☐ American Indian/Eskimo/Aleut
 - ☐ Asian/Pacific Islander
 - ☐ Black
 - ☐ White
 - ☐ Other/Unknown _____
- d. What is your family's ethnicity?
- ☐ Hispanic
 - ☐ Non-Hispanic
- e. What is the age of the primary caregiver? _____
- f. What is the health status of the primary caregiver?
- ☐ Excellent
 - ☐ Average
 - ☐ Poor
- g. What is the age of the individual with a disability? _____ ☐ Don't know
- h. Are you on a waiting list for services?..... ☐ Yes ☐ No ☐ Don't know
- i. Does your family receive:
- | | | |
|---|--|-------------------------------------|
| Case management/service coordination..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Family Support..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Other services/supports (specify) _____ | | |
- j. Does your family member receive:
- | | | |
|---|--|-------------------------------------|
| Case management..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| In-home supports..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Vocational services..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Transportation..... | <input type="checkbox"/> Yes <input type="checkbox"/> No | <input type="checkbox"/> Don't know |
| Other services/supports (specify) _____ | | |

Core Indicators Project – Family Survey

INFORMATION

	Most of the time N/A	Some of the time	Rarely	Don't Know	
1. Do you receive information about services and supports that are available to your family?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. Is the information easy to understand?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

CHOICE/PLANNING

	Most of the time N/A	Some of the time	Rarely	Don't Know	
3. Do you choose who helps you, such as your service coordinator, case manager, or home support provider?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. Is turnover of staff that work with you a problem?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
5. Do the staff work together with you to identify what you need as a family to support your family member?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
6. Do they present you and your family member with a range of options to meet your needs?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
7. Do they respect your choices and preferences?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

ACCESS

	Most of the time N/A	Some of the time	Rarely	Don't Know	
8. Do the supports offered reflect the needs of your <i>family</i> as well as your family member with a disability?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
9. Is your family getting the supports you need, such as respite care, training, or education?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
10. Are supports available when your family wants and needs them?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
11. In a crisis, are supports available in a timely manner?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
12. Do staff communicate with you in your preferred language?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

LINKAGES

	Most of the time N/A	Some of the time	Rarely	Don't Know	
13. Do the staff help you get other supports in your community, such as services offered through vocational rehabilitation programs, recreation departments, churches, or medical services?	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Core Indicators Project – Family Survey

14. Do the staff help you find family, friends, or neighbors who can provide some of the supports your family needs?

☐ ☐ ☐ ☐ ☐

Please use the space below for any other comments you would like to make.

Please note: It is our policy to keep all responses to this survey anonymous and confidential. However, if you have a specific concern that needs to be addressed and you would like someone to contact you, **please check here to waive confidentiality:** ☐

What is the best way to contact you? _____

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4/26/99

FAMILY SURVEY II

This is a second family survey that will be administered to guardians or families of adults who are receiving services and do not live at home.

The following proposed questions are taken from the Kansas Community Integration Project (also known as CIP) Guardian Survey:

- a. How would you rate the adequacy of information provided to you to help you participate in the person-centered plan process for the services your son/daughter/ward currently receives?
- b. How would you rate the effort of the agency providing residential services to your son/daughter/ward to involve you in important decisions (for example, medical, dental, where to live, roommate)?
- c. How would you rate the effort of the agency providing day services to your son/daughter/ward to involve you in important decisions (for example, where to work)?
- d. How would you rate how healthy and safe your son/daughter/ward is in his/her living arrangement?
- e. How would you rate how healthy and safe your son/daughter/ward is in his/her day services arrangement?
- f. How would you rate the level of involvement your son/daughter/ward has in community activities he/she/you value?
- g. How would you rate the overall services and supports your son/daughter/ward is receiving now?
- h. How would you rate the happiness of your son/daughter/ward in his or her current situation?

All ratings would be made using a 1-5 Likert scale.

Outstanding issues regarding the family survey(s):

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- How do we handle situations where the family is not involved because the consumer wants it that way? If we begin by selecting "guardians," will that work? Should we include other types of advocates, friends, etc.?

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4/26/99

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Data Sources

- HCBW payment files
- HCBW screening documents
- Consumer face-to-face interview
- Case manager interview/ survey
- Provider agency survey (residential/vocational)
- Family Survey
- Licensing results for every agency in 23 counties
- VA reports for each agency in 23 counties