



NASDDDS & HSRI

Background Information Data Collection – Best Practices for Quality

Agenda



BI data collection

– best practices for quality.

- Consent
- Data Sources for Background Info
- How States can help facilitate BI collection
- Recommendations for shadow interviews



Consent

NCI is seen as a QA activity

- Formal consent *often* not necessary
- Assent (agreement to participate) documented:

AGREEMENT TO PARTICIPATE: Did the person indicate to the surveyor that they agree to participate in the NCI survey discussion?

Yes No

- Discuss/document consent at annual meeting?
- ** Obtain consent (if required) before PS and BI
 - Won't spend time collecting PS/BI if person will not participate



Strategies for Describing NCI

Preparation helps!

Get in touch with self-advocacy groups, family networks in your state.

- They can let families know the survey is coming
- They can reinforce the importance of participation

Put the survey in context!

- Framing and wording matter!
- Have resources available for people in the form of a pamphlet, one-pager, etc.:
 - Here is why NCI is important
 - Here is what the state learns from your input/here is what the state has learned from NCI in the past.



Demonstrate how the info. is used

Your feedback is needed!

The Division of Developmental Disabilities would like to invite you to participate in the National Core Indicators (NCI) project.

Family Guardian Survey

South Dakota participates annually in the NCI Family Guardian Survey.

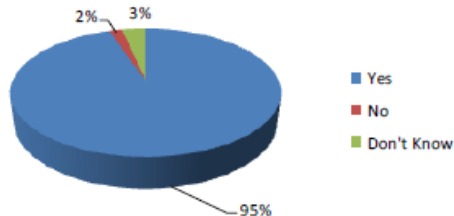
In 2014-2015 there were 315 families in South Dakota that participated in the Family Guardian Survey.

We invite you to provide your feedback on the 2015-2016 Child Family Survey.

For more information contact
Samantha Hynes
Program Specialist II
Samantha.Hynes@state.sd.us

Information gathered through the Family Guardian Survey is used to assess quality of services and drive system improvement changes in South Dakota.

Supports have made a positive difference



NATIONAL
CORE
INDICATORS™



To see all of the data from the NCI Family Guardian Survey 2014-2015 please visit
www.nationalcoreindicators.org or www.dhs.sd.gov/dd/nci

Tailored to survey respondents (Families and Guardians).

Demonstrates results from the survey.

Putting info in context of improvements

Several years of results in Washington state encourage ongoing participation to help inform the system.

Demonstrates results from the survey.

Washington State Department of Social and Health Services



Transforming Lives

The **Developmental Disabilities Administration** is inviting you to participate in the **National Core Indicators (NCI)** survey!

How do things change as a result of my feedback?

Year	Key Event/Policy	Impact/Action
2003	Necessary Supplemental Accommodation (NSA) policy implemented	<ul style="list-style-type: none"> Requires caseload members to identify someone, an NSA, to receive copies of all DDA notices NSAs assist the individual to understand the documents and exercise their rights
2006	Planned Action Notices (PANs) implemented	<ul style="list-style-type: none"> Provide a consistent communication to individuals on actions taken by the administration Inform individuals of their right to contest these actions
2008	Partnership with the Washington State Developmental Disabilities Council (DDC)	<ul style="list-style-type: none"> Launched "Informing Families, Building Trust" informingfamilies.org publishes bulletins and videos about developmental disabilities issues in Washington State Information available through e-newsletter subscriptions and Facebook
	"Road Map to Services" published	<ul style="list-style-type: none"> Provides an illustration of the administration's services

Percentage of families reporting that they always or usually received information about services and that the information was easy to understand from 1999 to 2014*



Year	Receives information about services (%)	Information received is easy to understand (%)
1999-2000	40%	63%
2001-2002	40%	62%
2003-2004	28%	46%
2005-2006	34%	51%
2007-2008	40%	50%
2009-2010	44%	55%
2011-2012	74%	72%
2013-2014	68%	68%

*Data source: NCI Adult Family Survey, WA State Data

For more information:
Contact DDA Program Manager, Kristin Ohler at kristin.ohler@dshs.wa.gov
Visit nationalcoreindicators.org



Data Sources for BI collection

Consider a wide range of sources-a mix of sources may be necessary

- Admin data
 - (Case management records, provider agency records)
- MMIS
- VR records

** BI may not be available in records, may be appropriate to ask during survey, but first examine options.



How States can facilitate BI data collection

- Develop a “codebook” for those responsible for data collection.
 - Indicates source for each piece of info

BI
collection
codebook
from
Oklahoma

BI-34 If this person lives in an Intermediate Care Facility for persons with ID/DD (ICF/ID), a specialized institutional facility or a group home, is it publicly or privately operated?

CHECK ONE.

- 1 Public
- 2 Private
- 99 Don't know
- 98 Not Applicable – person does not live in an ICF

BI-35 Is the person named on the lease?

- 1 No
- 2 Yes
- 99 Don't know
- 98 Not Applicable – person owns or is living with family or friends

BI-36 Does the person own his or her own home? (Is his/her name on the mortgage?)

- 1 No
- 2 Yes
- 99 Don't know

BI-37 Has this person ever lived (longer than a year) in an institutional setting such as a nursing home or ICF?

Check ALL THAT APPLY.

- 1 ICF, public
- 2 ICF, private
- 3 Nursing home
- 99 Don't know



Author
BI-34 – BI-36 → PHONE CALL

NOTE:

- **Public** refers to institutions that are STATE operated.
- **Private** refers to institutions operated by private organizations, individuals, or agencies.
 - It would be very unusual to code any individuals as 1 (Public). If you come across this, ask a senior team member for clarification. Their IP may reflect “state funded” if in a publicly funded placement

For C, CR, T, TR, or R whose residential placement is GHL, GHS, AGH or PW → almost always code as 2 (Private)

For C or CR who decline services but live in nursing home → if STATE operated → code as 1 (Public)
→ if run by private organizations, individuals, or agencies → code as 2 (Private)

For C, CR, T, TR, or R whose residential placement is SFC or ACS → Code as 98 “Not Applicable”

For C, CR, T, TR, or R whose residential placement is DLS → Code as 99 “Don't know”

For IR, NR → Code as 98 “Not Applicable”



Author
IP → under “History” section.

For C, CR, T, TR → automatically code as 1 (ICF, public)

For ALL other ID codes → PHONE CALL → ask for clarification if the individual has ever lived in an institutional setting or nursing home for ONE YEAR or longer.

Examples of ICF-IDs: NORCE, SORC, Hissom, Greer, The Children's Center-Bethany, Children's Medical Center-Tulsa.

If no/not applicable → write “N/A” in left margin and leave blank in ODES



How States can facilitate BI data collection

number	topic	Where to start to obtain
PS-1	Contact & Accommodations	Sample list
PS-2	Service coordinator	Initial call/ Meditech
PS-3	Information about Employ/Job Coach, CS Mgr	Sample list
PS-4	Proxy Respondents	Initial call
PS-5	Living arrangement	Initial call/ Meditech
PS-6	Support staff in the home during the day	Initial call
PS-7	Employment	Initial call/ Meditech
PS-8	Program or Workshop	Initial call
PS-9	Self advocacy	Initial call
PS-10	Self directed supports	Initial call/ Meditech
PS-11	Financial Management	Initial call/ Meditech
PS-12	Hiring/Managing Staff	Initial call
Number	topic	Where to start to obtain
BI-1	Survey code	Use sample list number
BI-2	Region	Sample list
BI-3	Zip Code	Sample list
BI-4	DOB	HCSIS - HCR
BI-5	Gender	HCSIS - HCR
BI-6	Race and Ethnicity	HCSIS Kathy Phillips will check on whether in MT; otherwise, ask at interview
BI-7	Guardian	Sample list/ Verify in Meditech
BI-8	Guardian's relationship to person	Meditech/Ask at Survey
BI-9	Marital status	HCSIS - HCR
BI-10	Is this person a parent?	SC or Ask at interview
BI-10a	Child or children live with the person?	SC or Ask at interview
BI-11	Is this person diagnosed with an intellectual disability (ID)?	Check yes to ID diagnosis
BI-11a.	If yes, what level of ID?	Check unknown to level
BI-12	Other conditions	HCSIS - HCR
BI-12a	What health conditions are noted in this person's record?	HCSIS - HCR
BI-13	Primary language	HCSIS - HCR
BI-14	Preferred means of communication?	Initial call
BI-15	Mobility	HCSIS - HCR

BI collection
codebook from
Massachusetts



Shadow Interviews

Two surveyors: both recording the same answers.

- Comparing answers post survey to assess accuracy and clarity

Shadow interviews can be used to:

- Assess surveyor readiness
 - Understands aim of questions
 - Probes and records responses correctly
 - Courteous and respectful
- Training purposes (identify areas of need)

