National Core Indicators for Intellectual and Developmental Disabilities (NCI-IDD) Overview

February 2025



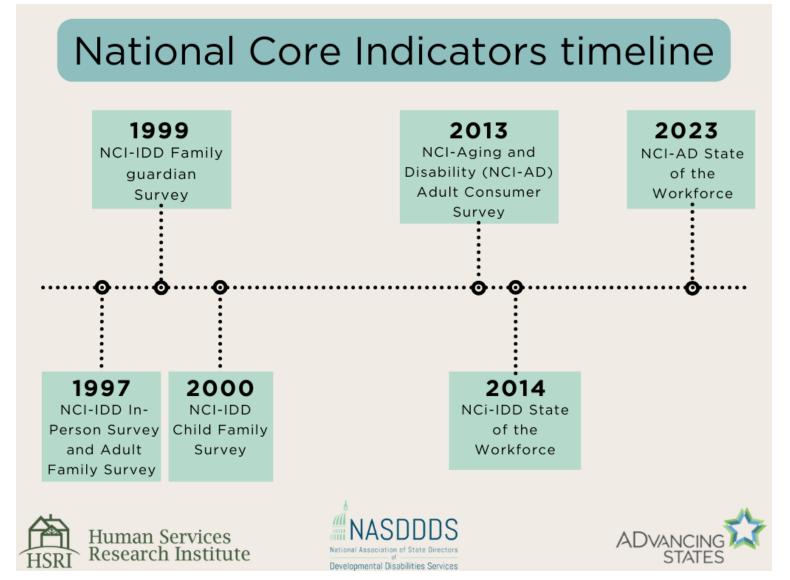
National Core Indicators (NCI)

NCI tools collect data on performance and quality of life indicators directly from:

- (1) people who use disability and/or aging services systems;
- (2) families; and
- (3) those who deliver services

Participating states:

- NCI-IDD IPS and Family Surveys: 48
- NCI-AD: 26
- State of the Workforce: 30 states for the NCI-IDD SoTW, and 2 states for NCI-AD SoTW





Goals of NCI



recognized set of performance and outcome indicators for aging & disability (including IDD) service systems



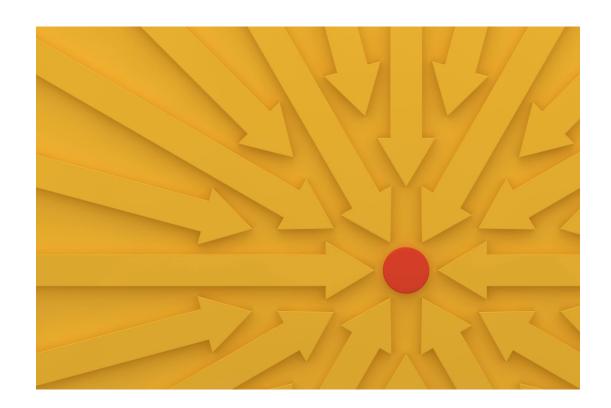
Use valid and reliable data collection methods & statistical techniques to capture information directly for people who use services



Report individual state results and national benchmarks of indicators of system-level performance



Why do state DD systems participate in NCI? Why measure quality?



Alignment with values and policy intent

Effectiveness

Course correction

Accountability



Federal Government Interest in LTSS Quality Measurement

Adult Core Set Health Care Quality Measures Centers for Medicare & Medicaid Services (CMS) Medicaid and Children's Health Insurance Program (CHIP) Scorecard **HCBS Quality Measures Set (QMS)** HCBS Settings Rule – reporting and engagement using NCI data CMS Consensus-based Entity (CBE) Increasing interest in data linkages



NCI-IDD information comes from people who receive, experience, provide services









National Core Indicators In-Person Survey (IPS) offers a unique view of the state service system

- Individual characteristics of people receiving services
- Outcomes by where people live (residence type)
- Activities they engage in during the day including work outcomes
- The nature of their experiences with the supports they receive (e.g., with case managers, ability to make choices, selfdirection)
- The context of their lives friends, community involvement, safety
- Health and well-being, access to healthcare



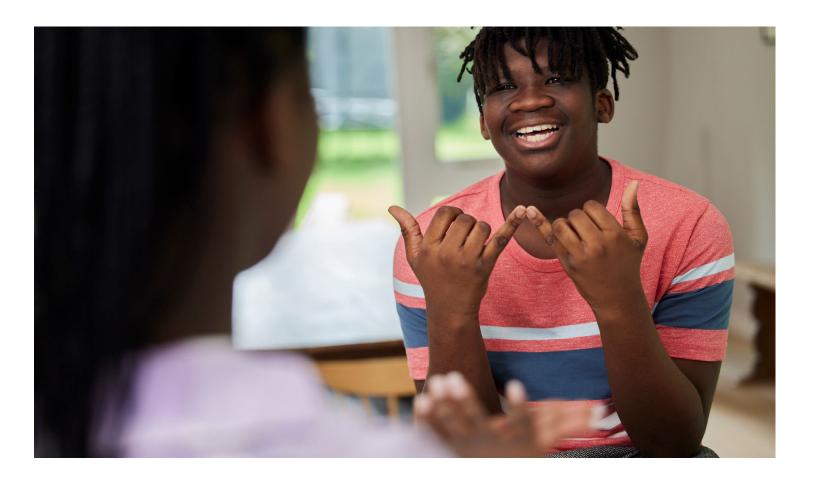
IPS Subdomains

The IPS examines core elements of person-centered planning, outcomes, and satisfaction within domains such as.....

In-Person Survey







Today we'll discuss: NCI In-Person Survey

Standardized, face-to-face meeting with the person receiving services

No pre-screening procedures (random sample)

Adults Only (18 and over)

Proxy allowed for portion

Takes approximately 50 minutes



Why is the **NCI** Important? asks people how they are doing "Are your families doing healthy?"



Things to know about the IPS



NCI In-Person Survey

Protocols ensure the survey is:

- Voluntary
- Confidential
- Not used to monitor individual providers or for service planning

Survey Structure:

Pre-Survey

Background Information collected prior to survey, from records

Section 1 – In-person: no proxies allowed. (e.g., "Do you like your home?")

Section 2 – In-person: proxies may respond. (e.g., "Can you lock your bedroom door?")



Can you trust NCI IPS data?

Data integrity and reliability of NCI results are assured

Protocols and guidance from NCI for the NCI coordinators in each state

Protocols for sampling, documentation of samples used

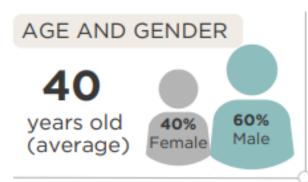
Clear and consistent training of data collection personnel in the NCI approved protocols for data gathering

Use of online electronic survey application (ODESA)

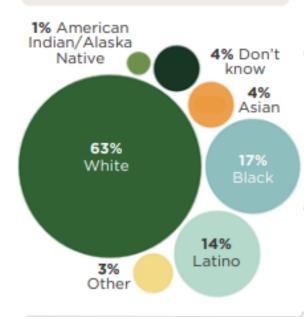
Data cleaning and validation with states prior to analysis

Review of draft report by states





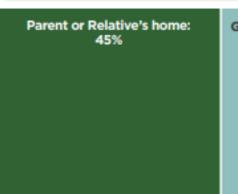
RACE AND ETHNICITY



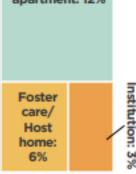
RECEIVES MEDICARE

47%

RESIDENCE TYPE & LOCATION



Group home: 31% Own home or apartment: 12%



82% Metropolitan

10% Micropolitan

5% Small town

2% Rural

LEVEL OF GUARDIANSHIP

51% No guardian

11% Has guardian but level unknown

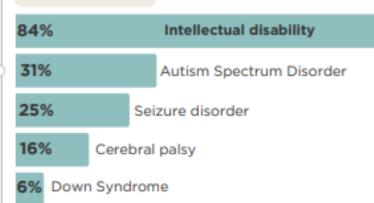
26% Full guardianship

MOBILITY

10% Limited guardianship 3% 2022-23 -Don't

know

DIAGNOSIS



Note: Diagnoses are not mutually exclusive

Moves self with aids or uses wheelchair,

Moves self with aids or uses wheelchair, while 77% move without use of aids



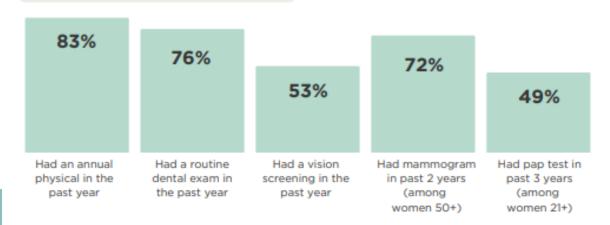
CHOICE AND DECISION-MAKING

Person had Someone Person Who chose... chose some input else chose Your regular 46% **37**% **17**% day activities The place 24% 31% 46% vou live The people 23% 20% **57%** you live with



18% of respondents chose their staff, and 41% had their staff assigned but can request a change

ACCESS TO HEALTH CARE



RIGHTS AND RESPECT

80%

Report that others ask before coming in their bedroom

44%



Report they can stay home if others go out (for those not living in own home or apartment)

SATISFACTION

81% Like how they usually spend their time during the day

57% Have used telehealth and like using it



The average respondent says they are satisfied with their level of participation in at least 3 out of 5 community activities (e.g., go shopping, go out for entertainment).



How are data used?

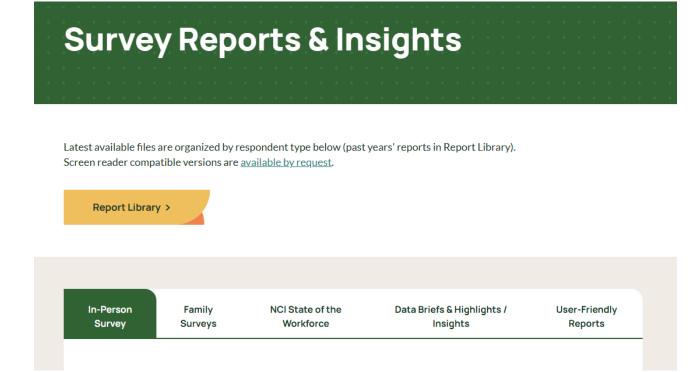


National and State Reports

 Reports available on NCI website at: https://idd.nationalcoreindicators.org/

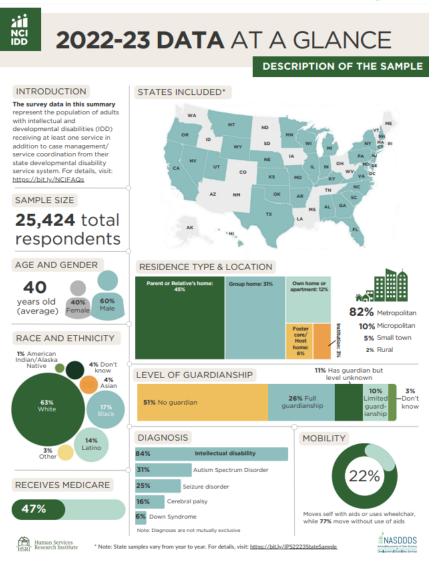
National reports include states ranked as significantly above, below, within national average.

At-a-Glance report summary of all NCI reports

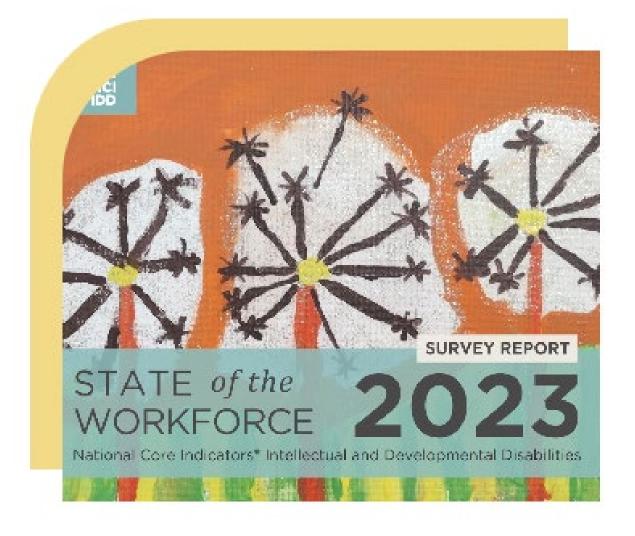




Sample Page: At-a-Glance Report (2022-23)







Residential, In-Home, and Non-Residential Agencies

Size of Agency reporting

Tenure

Turnover

Wages – Starting and

Overall

Benefits

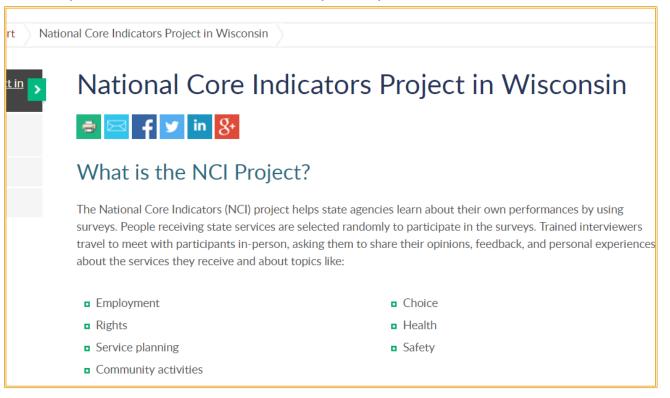
Comparison to Minimum

Wage



How do states use data?

Example: State web-site developed by WI



CMS Waiver reporting requirements

Quality assurance/ improve services

State-by-state comparisons

Monitor outcomes by residential setting (community transition)

Quality and DD Councils review and identify statewide priority

Reports to State Legislatures



For more information:



Laura Vegas

lvegas@nasddds.org

Dorothy Hiersteiner

dhiersteiner@hsri.org



South Dakota Data (2022-2023)

States are required to complete valid surveys with a sample size large enough to meet a minimum 95% confidence level and +/- 5% margin of error based on the size of the total eligible population in order to be included in the NCI-IDD national reports. Typically, this means states must produce a final sample of 400 surveys.

SD did not complete enough surveys during the last collection cycle and did not receive a state report. The following is SD's data, combined with published data from states that completed their sample for comparison. NCI-IDD advises using the SD data with caution. Our hope is that it is directionally helpful. We have included the "n" to demonstrate sample size for each question.



HCBS Quality Measure Set

National Core Indicators® - Intellectual and Developmental Disabilities (NCI®-IDD)





National Report 2022-23

NCI-IDD In-Person Survey Measures

Included in the HCBS Quality Measure Set

- The NCI-IDD In Person Survey is one of CMS's accepted "experience of care" surveys that is part of the Quality Measure Set.
- While most of the QMS is currently voluntary for states, Money Follows the Person states like South Dakota must begin reporting on a subset of the QMS in 2026, using 2025 data.
- The subset includes questions on Community Inclusion, Person-Centered Care, Safety, and Transportation
- The following slides share data related to QMS indicators



Social Connectedness (Proportion of People Who Often Feel Lonely)*

Ranking	State	Average within State		N
1	OK		22%	238
1	WI		22%	127
3	IN		20%	748
4	UT		17%	226
5	DE		16%	234
5	OR		16%	262
7	NV		15%	347
7	TX		15%	204
7	KS		15%	249
10	AR		14%	283
10	MD		14%	312
10	CT		14%	316
10	NY		14%	918
10	AL		14%	241
-	NCI-IDD Average		13%	
15	SD		13%	
15	DC		13%	207
15	NJ		13%	212
15	VA		13%	338
19	SC		12%	265
20	FL		10%	226
20	GA		10%	218
20	WY		10%	259
23	NC		9%	311
23	MT		9%	243
23	HI		9%	134
23	NH		9%	200
23	MI		9%	358
28	MO		8%	244
28	MN		8%	204
28	NE		8%	324
31	PA		7%	363
32	IL		4%	216
33	KY		2%	195



Transportation Availability Scale (Proportion of People with Adequate Transportation)*

Ranking	State	Average within State	I	V
1	AR		96%	285
2	GA		95%	216
2	SD		95%	147
4	KS		93%	235
4	PA		93%	358
6	CT		91%	312
6	NC		91%	321
6	OK		91%	237
6	VA		91%	347
10	HI		90%	136
10	IL		90%	212
12	IN		89%	745
12	MN		89%	208
12	MO		89%	247
15	NY		88%	915
15	SC		88%	270
15	WY		88%	262
18	DE		87%	235
18	NJ		87%	219
20	AL		86%	248
20	MI		86%	361
20	NV		86%	342
20	OR		86%	255
-	NCI-IDD Average		86%	14,553
24	MD		85%	313
25	MT		84%	238
26	UT		83%	222
27	WI		82%	120
28	DC		80%	203
29	NE		78%	318
29	TX		78%	206
31	FL		76%	230
32	KY		72%	201
33	NH		68%	198



Percentage of People Who Report that They Helped Make Their Service Plan*

Ranking	State	Average within State	N	
1	GA		94%	401
2	KY		90%	424
2	SD		90%	168
4	MI		89%	644
5	FL		87%	516
5	UT		87%	326
7	KS		83%	342
7	MN		83%	392
7	NE		83%	391
10	IL		81%	380
11	MD		78%	505
11	NV		78%	348
11	WY		78%	398
11	TX		78%	384
11	MO		78%	391
11	IN		78%	999
17	AL		77%	451
18	NH		76%	390
19	MT		75%	347
19	WI		75%	333
19	NY		75%	1,612
-	NCI-IDD Average		75%	23,789
22	SC		73%	482
22	PA		73%	612
24	AR		72%	382
25	OR		71%	407
26	DC		70%	310
27	VA		69%	739
28	OK		68%	380
29	NJ		66%	427
30	NC		65%	562
31	CT		64%	572
32	DE		61%	351
33	HI		50%	347



Percentage of People Who Report that Staff Come and Leave When They Are Supposed To*

Ranking	State	Average within State	N	
1	AR		97%	228
1	MO		97%	144
1	IL		97%	93
4	SC		96%	193
4	NC		96%	183
6	KY		95%	39
7	IN		94%	566
7	VA		94%	188
9	WI		93%	46
9	PA		93%	116
9	HI		93%	69
12	OK		92%	105
12	UT		92%	132
14	MN		91%	96
15	DE		90%	42
-	NCI-IDD Average		90%	7,433
15	MT		90%	215
15	MI		90%	183
15	MD		90%	173
19	NY		89%	406
19	AL		89%	92
19	GA		89%	98
22	FL		88%	133
22	SD		88%	74
24	DC		87%	153
24	NV		87%	225
26	NJ		86%	81
26	CT		86%	221
28	OR		85%	60
28	NE		85%	282
30	NH		84%	73
31	KS		83%	155
32	WY		82%	146
33	TX		79%	77



Respect for Personal Space Scale

(Proportion of People with Personal Space Respected in their Home)*

Ranking	State	Average within State	N	
1	AR	_	93%	294
1	VA		93%	361
1	MN		93%	208
1	GA		93%	216
5	IL		92%	223
6	PA		91%	371
7	SC		90%	276
8	NE		89%	340
8	NH		89%	200
10	NJ		88%	227
10	WI		88%	121
10	IN		88%	776
-	NCI-IDD Average		88%	15,132
13	MT		87%	247
13	MI		87%	367
13	DE		87%	239
13	WY		87%	263
13	NY		87%	937
13	SD		87%	149
19	TX		86%	208
19	OK		86%	246
19	NC		86%	345
19	AL		86%	259
19	CT		86%	327
19	KS		86%	258
19	NV		86%	353
19	MO		86%	251
27	OR		85%	273
27	FL		85%	232
27	DC		85%	215
27	UT		85%	231
31	HI		83%	123
32	MD		81%	327
33	KY		77%	196



Can Stay at Home When Others Leave*

Ranking	State	Average within State	N	
1	SD		80%	124
2	VA		66%	698
3	CT		60%	533
4	MT		58%	298
5	MD		57%	493
5	UT		57%	321
7	NV		54%	364
8	WY		51%	327
8	OR		51%	353
10	DC		49%	311
10	IL		49%	369
10	FL		49%	498
13	PA		48%	649
13	MN		48%	375
13	DE		48%	408
16	SC		47%	470
16	WI		47%	301
16	NY		47%	1,531
19	CA		45%	8,220
19	MO		45%	364
-	NCI-IDD Average		44%	23,242
20	NJ		44%	421
21	AL		43%	446
22	KS		41%	342
23	MI		40%	604
24	GA		39%	380
25	NE		38%	360
26	IN		37%	1,037
27	AR		36%	345
28	TX		33%	371
29	HI		29%	342
30	OK		27%	362
31	NC		25%	561
32	NH		21%	372
33	KY		11%	416



Life Decision Composite Measure (Proportion of People Who Report Making Choices in Life Decisions)*

Ranking	State	Average within State	N
1	SD	80	% 109
2	FL	79	% 530
3	NE	72	.% 406
4	GA	71	% 406
4	IL	71	% 400
4	MO	71	% 402
7	OK	70	% 399
8	KY	69	% 435
8	MI	69	% 668
8	VA	69	% 762
11	OR	67	'% 418
12	AL	64	.% 478
12	AR	64	% 416
12	NC	64	% 593
15	KS	63	393
16	NV	62	413
17	PA	60	% 716
18	SC	59	% 511
18	UT	59	346
20	MD	58	531
-	NCI-IDD Average	58	14,524
21	HI	56	351
22	MT	55	
23	CT	54	% 600
24	IN	52	1,076
25	TX	50	% 410
26	NJ	47	% 458
27	NY	40	% 1,653
28	NH	35	399



Person-Centered Goals

(Proportion of People whose Service Plans Include Things That Are Important to Them)*

Ranking	State	Average within State		N
1	SC	9	97%	189
1	AR	9	97%	220
1	WY	(97%	215
1	IL	(97%	181
1	MN		97%	179
1	SD	(97%	109
7	VA	9	96%	265
7	MD		96%	230
7	FL		96%	203
7	MO		96%	203
7	PA		96%	287
7	GA		96%	206
13	WI		95%	86
13	NJ		95%	150
13	IN		95%	629
13	OK		95%	214
13	MT		95%	231
13	CT		95%	225
13	DC		95%	130
20	NC		94%	269
20	AL		94%	193
20	UT		94%	175
20	NV		94%	247
24	OR		93%	199
24	KS		93%	214
24	NY		93%	816
-	NCI-IDD Average		93%	10,816
24	DE		93%	136
28	HI		92%	92
28	NE		92%	214
30	KY		91%	186
31	NH		90%	154
32	MI		88%	330
33	TX	8	84%	167



Satisfaction with Community Inclusion Scale (Proportion of People Satisfied with Level of Participation in Community Inclusion Activities)*

Ranking	State	Average within State	N	
1	KY	_	80%	198
2	PA		66%	384
3	NE		65%	334
3	MN		63%	207
5	MT		63%	241
5	GA		62%	221
5	KS		62%	266
8	TX		62%	204
8	MO		61%	259
10	WI		61%	128
11	WY		60%	264
12	NH		59%	208
12	FL		57%	245
14	MI		57%	367
14	DE		56%	238
14	AR		56%	293
14	OR		56%	291
-	NCI-IDD Average		56%	15646
18	SD		55%	188
19	NY		54%	929
20	AL		53%	267
20	IL		53%	222
20	UT		53%	221
23	VA		51%	384
24	NJ		50%	239
24	NV		50%	342
26	IN		49%	786
26	MD		49%	324
26	NC		49%	353
29	DC		48%	217
29	CT		48%	333
29	SC		48%	275
32	HI		46%	142
33	OK		43%	249



Proportion of People Who Had an Annual Physical Exam within the Past Year*

Ranking	State	Average within State		N
1	NJ	_	98%	444
2	KY		97%	414
3	GA		96%	398
3	OK		96%	400
5	SD		95%	170
6	AR		95%	398
6	AL		95%	456
6	CT		95%	596
6	FL		95%	525
10	NH		94%	383
10	MI		94%	507
12	SC		93%	481
12	PA		93%	627
12	NE		93%	416
15	IL		92%	330
15	MO		92%	395
15	UT		92%	311
15	MT		92%	353
15	IN		92%	1,034
20	MD		90%	495
21	TX		88%	382
21	NC		88%	544
21	MN		88%	382
-	NCI-IDD Average		83%	23,463
24	WY		82%	284
25	WI		81%	241
25	HI		81%	342
27	KS		80%	305
27	OR		80%	379
29	VA		78%	743
30	DC		77%	133
31	NV		73%	373
32	DE		60%	238
33	NY		53%	1,609



Proportion of People Who Had a Routine Dental Exam within the Past Year*

Ranking	State	Average within State	N	
1	SD		97%	168
2	NE		91%	418
3	NJ		89%	422
4	CT		88%	586
5	AL		87%	432
6	IN		86%	1,028
6	KY		86%	381
8	SC		85%	453
8	UT		85%	273
10	PA		84%	583
10	MN		84%	377
12	MT		83%	346
13	IL		81%	313
14	GA		79%	387
14	DE		79%	207
14	TX		79%	383
14	MO		79%	382
18	NH		78%	346
18	DC		78%	127
18	MD		78%	489
21	OK		77%	396
21	FL		77%	509
-	NCI-IDD Average		76%	22,553
23	KS		75%	259
23	NC		75%	493
25	MI		72%	434
26	AR		70%	318
26	OR		70%	386
28	WI		67%	223
29	WY		66%	320
30	NY		62%	1,480
31	VA		59%	724
32	NV		56%	277
33	HI		52%	269



Proportion of People Who Have Had an Eye/Vision Exam within Past 5 Years*

Ranking	State	Average within State		N
1	GA		79%	363
2	DC		78%	96
3	IL		77%	285
3	SD		77%	164
5	SC		73%	439
6	NJ		71%	384
7	KS		68%	238
7	HI		68%	299
9	KY		67%	309
10	PA		66%	535
11	OK		65%	393
12	MN		64%	365
13	MD		62%	448
14	AL		61%	401
15	AR		59%	330
16	DE		58%	93
16	CT		58%	559
18	IN		55%	1,005
18	NE		55%	417
18	UT		55%	164
18	MO		55%	373
-	NCI-IDD Average		53%	20,921
22	NH		53%	325
23	VA		51%	325
24	NC		49%	390
25	WI		47%	215
25	OR		47%	365
27	WY		45%	319
27	FL		45%	482
29	MI		43%	343
30	MT		42%	327
30	TX		42%	371
32	NV		41%	196
32	NY		41%	1,490



Proportion of People Who Have Had a Hearing Test within Past 5 Years*

Ranking	State	Average within State	N
1	DC	100%	66
2	PA	85%	338
2	HI	85%	283
4	UT	63%	92
5	IL	62%	198
6	CT	59%	478
7	NE	56%	393
8	IN	53%	938
9	SD	52%	60
10	NJ	51%	315
10	AL	51%	316
12	KY	50%	159
12	NY	50%	995
14	KS	48%	147
15	AR	47%	237
-	NCI-IDD Average	47%	17,385
15	SC	47%	282
17	NC	46%	272
18	WY	45%	317
19	MI	44%	217
19	MT	44%	219
19	NV	44%	73
22	MN	43%	308
23	MD	42%	354
24	NH	41%	213
25	VA	40%	230
25	MO	40%	270
27	FL	36%	395
28	WI	33%	105
29	OK	30%	366
30	GA	28%	344
30	TX	28%	337
32	OR	21%	322



Proportion of Women Over 21 Who Have Had a Pap Test Screening at the Recommended Interval*

Ranking	State	Average within State	N	
1	NV		70%	67
2	GA		67%	139
3	UT		66%	44
4	PA		63%	150
4	CT		63%	195
6	AL		62%	120
6	NJ		62%	133
7	MD		60%	161
8	KY		59%	75
9	NY		57%	397
10	IL		56%	78
10	NE		56%	121
12	SC		55%	137
13	VA		54%	114
14	SD		52%	29
15	MN		50%	117
15	IN		50%	316
17	MT		49%	94
-	NCI-IDD Average		49%	6,997
18	MO		48%	116
19	KS		47%	90
20	AR		46%	92
21	FL		45%	174
21	OK		45%	135
21	OR		45%	122
24	NC		43%	130
24	WI		43%	79
26	TX		42%	144
26	WY		42%	130
28	MI		40%	121
28	DE		40%	117
30	HI		38%	88
31	NH		28%	109



Proportion of Women Over 50 Who Have Had a Mammogram within Past 2 Years*

Ranking	State	Average within State	N	
1	SD		90%	20
2	CT		87%	83
3	PA		84%	93
4	MD		82%	55
4	FL		82%	44
4	NJ		82%	55
7	OK		79%	57
7	AL		79%	52
9	IN		78%	137
9	SC		78%	54
11	OR		76%	45
12	GA		75%	69
13	NE		74%	42
14	AR		72%	36
-	NCI-IDD Average		72%	2,605
14	MI		72%	43
16	IL		71%	35
16	MN		71%	35
18	NC		70%	44
18	NY		70%	172
20	MO		66%	38
21	NH		65%	43
21	MT		65%	51
23	KY		64%	36
24	KS		61%	31
25	WY		56%	43
26	VA		55%	44
27	HI		49%	41
28	WI		43%	28
29	NV		42%	31
30	DE		35%	60



Proportion of People Ages 45 to 75 Who Have Had Recommended Screening for Colorectal Cancer*

Dankings		Colonoscopy	•		Never had	Dank	
Rankings -		•	-	FIT in past		Don't	
Colonoscopy	State	years	years	year	screening	Know	N
1	CT	68%	0%	5%	14%	14%	235
	NJ	57%	0%				
	NE	48%	0%				
	OK	45%	1%				
	KS	42%	4%				
	MN	42%	2%				
	WY	41%	10%				
8	MT	40%	1%				
9	TX	39%	2%	0%	39%		
	NH	38%	2%				
10	SD	38%	1%		8%		
	MO	37%	3%				
13	FL	36%	0%	5%	38%	20%	161
14	GA	35%	0%	1%	37%	26%	210
14	IL	35%	1%	10%	17%	37%	154
14	IN	35%	1%	4%	26%	35%	423
17	MD	34%	1%	1%	24%	37%	156
18	SC	33%	0%	2%	18%	48%	202
	NCI-IDD						
-	Average	32%	1%				
	NC	31%	1%				
	PA	30%	1%				
	OR	29%	0%				
	KY	27%	1%	5%	12%		
23	AL	23%	5%				
	UT	22%	0%				
25	AR	19%	1%			55%	
25	MI	19%	3%	3%			219
27	DE	18%	3%	3%	5%	77%	147
27	WI	18%	1%	4%	18%	59%	138
29	DC	16%	0%	1%	0%	84%	97
29	VA	16%	0%	4%	18%	63%	250
31	HI	15%	0%	11%	22%	54%	94
32	NV	11%	0%	0%	7%	82%	133



Moving Forward

South Dakota's data must be entered into the NCI data system by June 30, 2025. What are reasonable milestone dates we can agree upon to reach this deadline together?

