Intellectual and Developmental Disabilities

Assessing Privacy: What Aspects of Privacy are Reported and Whose Experiences are Not Represented?

--Manuscript Draft--

Manuscript Number:	IDD-D-24-00082R3
Article Type:	Research
Keywords:	Privacy; intellectual and developmental disability; Missing data; National Core Indicators
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Abstract:	Standards of privacy are required for people with intellectual and developmental disabilities (IDD) receiving Medicaid Home and Community-Based Services (HCBS). The National Core Indicators In-Person Survey is one tool that people with IDD use to assess the presence, absence, and quality of their privacy. This study describes privacy assessments from a sample of 2,196 service users with IDD from 2021–2023 and shows that patterns of missing assessments are predicted by level of intellectual disability and non-verbal forms of communication. Missing privacy data, especially from those at greatest risk, poses a threat to community integration for people with IDD and requires the development of more accessible methods for collecting personal outcome data.

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Abstract

Standards of privacy are required for people with intellectual and developmental disabilities (IDD) receiving Medicaid Home and Community-Based Services (HCBS). The National Core Indicators In-Person Survey is one tool that people with IDD use to assess the presence, absence, and quality of their privacy. This study describes privacy assessments from a sample of 2,196 service users with IDD from 2021-2023 and shows that patterns of missing assessments are predicted by level of intellectual disability and non-verbal forms of communication. Missing privacy data, especially from those at greatest risk, poses a threat to community integration for people with IDD and requires the development of more accessible methods for collecting personal outcome data.

Keywords: Privacy, intellectual and developmental disability, missing data, National Core Indicators

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Introduction

The personal privacy of people with disabilities is an extremely important issue for people with disabilities, family members, advocates, and support professionals (Brand et al., 2020). Privacy is widely expected in homes and other spheres of daily living, and it has been interpreted by the U.S. Supreme Court as a right implied throughout the U.S. Constitution (*Griswold v. Connecticut*, 1965). The Court's *Olmstead* decision (1999), interpreting the integration mandate in the Americans with Disabilities Act of 1990 (ADA), further described privacy, along with opportunities for relationships, autonomy, and community participation, as a distinguishing factor of community integration. Similarly, with its emphasis on integration, autonomy, and protection from coercion, the Centers for Medicare and Medicaid's (CMS) Home and Community-Based Services (HCBS) Settings Rule outlines basic standards for privacy. These include concrete examples of the privacy one should expect when receiving services, including the privacy of their own physical space (i.e., unit) with lockable doors, the right to personalize their space, the right to have visitors of their choosing, and autonomy over schedules and activities (CMS, 2014). Documented justification must be provided when privacy rights are restricted. However, little is known about how Medicaid-funded intellectual and developmental disability (IDD) supports and services affect privacy or how missing data in national surveys may contribute to privacy disparities for specific subgroups of people with IDD.

Current policy mandates supporting privacy rights arise against a historical context of segregation in which people with IDD regularly had their privacy rights abridged. They endured physical separation, receiving services in institutional, "quasi-carceral" environments (Ben-

Moshe, 2020). Infringements on the privacy of people with IDD have been framed as necessary for ensuring support and safety (Lord et al., 2012). However, over-surveilling people with IDD further reinforces their stigmatization and heightens their anxiety (Chung et al., 2016; Nair, 2024). Close scrutiny of activities and relationships compromises both personal privacy and autonomy and may lead people to believe that their actions are wrong or even dangerous.

Privacy grants a person control over voluntary solitude and individual spaces. With territorial privacy people can exert control over the permeability of liminal spaces— they can choose who is allowed near the physical areas surrounding their bodies and belongings (Chalghoumi et al., 2019). Another salient type of privacy is communication privacy in which people can communicate with others by mail, email, or conversation without the fear of surveillance from uninvited parties, whether hackers or support persons. Each type of privacy is distinctly important, especially in light of potential privacy violations for people with IDD that can occur in homes and virtual spaces (Brand et al., 2020; O’Brolchain & Gordijn, 2019). Because privacy influences when and how one engages with the world, its provision may grant opportunities to form personal identities.

The National Core Indicators In-Person Survey (NCI-IPS), developed by Human Services Research Institute (HSRI) and the National Association of State Directors of Developmental Disability Services (NASDDDS, n.d.), has been one method used to monitor, at the systems level, the extent to which services and supports promote contexts that lead to mandated privacy outcomes. The NCI-IPS includes several items designed to measure privacy in residential environments, including the choices and contexts related to territorial and communication privacy. Ticha and colleagues (2018) selected six NCI-IPS items that aligned with the “Respect for Privacy” article of the Convention on the Rights of Persons which was signed by the United States (though not ratified) and broadly aligns with U.S. law (e.g., Rehabilitation Act; Americans with Disabilities Act, ADA). Houseworth and colleagues (2019) also attempted to measure home privacy from NCI-IPS items, and two items have also been used to monitor personal privacy (Authors et al., 2022). Each of these cases offered a narrow interpretation of privacy, sharing little about how— or even if— people with IDD assessed their privacy directly.

Furthermore, NCI-IPS studies rarely report whether data are missing at random (MAR) or missing completely at random (MCAR). MAR refers to patterns and probabilities of missingness that are associated with observed variables elsewhere in a dataset. In contrast, MCAR data show no systematic pattern—missingness is unrelated to observed variables.

When missingness is reported in NCI-IPS research, it typically appears in items from sections that allow proxy responses (e.g., Authors, 2021; Authors, 2022). In these cases, missingness does not typically exceed 10%. However, it has been underreported in sections where only service users are allowed to describe and assess their lived experiences. Responsive systems can only adapt policies and practices based on available data. Missing data may have consequences for those excluded and may even reinforce disparities in marginalized groups, such as those with the greatest support needs (e.g., King et al., 2020).

Present Study

Agencies administering HCBS waivers need reliable methods to monitor personal privacy, ensure that people are not over-surveilled, and protect individuals' privacy rights. Previous operationalizations of privacy using NCI-IPS items possessed a limited scope that did not match broader privacy goals outlined in CMS's Settings Rule (2014). In this paper, we report on a broad operationalization of privacy outcomes over multiple years in one southeastern state and examine whether all service users with IDD equally submitted assessments of the privacy they have—or lack—in their daily lives. To address these aims, we pose two guiding research questions:

> **Research Question 1**: How do people with IDD using HCBS services in one U.S. state describe their privacy experiences over three consecutive years?
> **Research Question 2**: Do personal characteristics predict missingness of privacy items, and if so, what groups have limited opportunity to describe the status of their privacy?

Methods

The methods used in this study were reviewed and approved by the Institutional Review Board of the authors' affiliated university. The authors do not have any conflicts of interest to declare.

Participants

We used data from [state name redacted]'s 2021–2023 NCI-IPS (n = 2,196). Using the Background section of the NCI-IPS, we examined participants' age, gender, race, level of intellectual disability (ID), preferred means of expression, and type of residence. Across the full sample, the average age of participants was approximately 41 years, with a slight majority of participants identifying as male (61%). Most of the sample was White (63%), followed by Black/African American (30%). The severity of most people's ID was described as "mild" (32%) or "moderate" (41%) while 27% were described as having "severe" (18%) or profound (9%) ID. Finally, the majority of participants (76%) preferred spoken expression, and 35% lived in a parent's or relative's home. Personal characteristics and residential contexts are presented in Table 1.

Measures

Participating states administer NCI-IPS surveys to adults (age 18 or older) with IDD who used at least one state-funded HCBS waiver service in addition to case management. The NCI-

IPS consists of three sections: (1) the background information section, which includes demographic, health, and service and support questions completed by case managers; (2) Section I of the IPS, which may only be completed by the person with IDD and contains questions about personal opinions and service satisfaction; and (3) Section II of the IPS, which includes questions about rights, choices, community participation, and other topics. Section II is supposed to be answered by the person with IDD directly whenever possible, though proxy respondents may be used as needed.

This study used NCI-IPS privacy items drawn from prior research (Houseworth et al., 2019; Authors, 2022; Ticha et al., 2018). Additional privacy items measured phone and internet use. Privacy items came from Sections I and II of the NCI-IPS (see privacy item code names, wording, and response options in Table 2). Items were recoded from their original format to one where lower values represented less privacy and higher values indicated more privacy. Because proxy respondents were not permitted to assess subjective or personal aspects of privacy, all items from Section II reflect objective conditions and procedures of the person's residential environment.

Data Analysis

Descriptive Analysis

To answer Research Question 1 concerning how people with IDD describe their privacy experiences over three consecutive years, we conducted a series of descriptive analyses across demographic and privacy data. We calculated frequencies for privacy items for each NCI-IPS sample year, as well as across the full sample (see Table 3), in which data were combined across years to summarize privacy responses for HCBS service users with IDD. A chi-square analysis of independence was used to determine whether the proportions of privacy responses varied by sample year.

Missing Data

Interviewers use proxy determination items to assess whether participant responses reflect an understanding of items. The NCI-IPS methodology provides participants with examples and counter examples of valid responses to support this determination. If responses are deemed invalid, interviewers are instructed to skip Section I and instead complete Section II with proxy respondents. These decisions, by default, result in missing responses for all Section I items.

HSRI reported that valid responses to items in 2022–2023 NCI-IPS Section I ranged from 36% to 84% (HSRI & NASDDDS, 2024). Therefore, there are instances when proxy determination responses are considered valid, but participants either choose to not additional questions or exhibit difficulty responding to Section I items, even when interviewers rephrase them using more familiar language. Although interviewers aim to support participants in answering as many questions as possible, they may skip remaining Section I items if participants exhibit behaviors indicative of increased stress or choose to stop. In these cases, NCI-IPS interviewers would code unclear, unintelligible, or non-valid (i.e., unrelated to response options) responses as “Don’t Know”. Therefore, in some cases, “Don't Know” and missing responses were functionally equivalent. For the purposes of analysis “Don’t Know” and “Not Applicable” were both treated as missing. Items including *enterhome, enterbedroom, bealone*, *havephone,* and *keyhome* did not include “Not Applicable” as a response option. The remaining four items included either a “Don’t Know” or “Not Applicable” response option. At the end of Section I, interviewers may also report whether some or none of the responses were valid.

Multiple imputation, in which available data is used to replace missing data, was not used in the study. For items with 50% or greater missingness, imputation was judged to compromise the face validity of the results. Choosing not to impute also preserved the actual voices of service users with IDD in the analysis.

Logistic Regression. To determine whether our data were MCAR, we used Little's (1988) test and found that the data could not be treated as MCAR ($p < .001$). This indicated that missingness was likely associated with other variables in the dataset, including participant characteristics. We then conducted logistic regression analyses to test potential predictors of missingness. For this analysis, missingness was treated as a binary outcome, with 1 indicating "missing" and 0 indicating "not missing."

Each of the predictors of missingness included in the logistic regression came from the Background section of the NCI-IPS. These predictors included the personal characteristics of participants, including their level of ID, type of residence, and preferred means of expression. We chose these specific characteristics as predictors because research suggests that having a higher level of ID and communicating through non-spoken language (i.e., sign language, gestures, communication aids) can prevent people from fully participating in research (e.g, Mietola et al., 2017). Residence type was also included as a predictor because some items were not applicable to people who lived by themselves (e.g., *stayhome*). Survey year was also included as a predictor of missingness. In 2020–21, the year after COVID-related shutdowns prematurely ended in-person data collection in many states, NCI introduced new interview methodologies. Most notable was the shift from in-person interviewing to a remote surveying protocol using a video conferencing interview format. All new and returning NCI-IPS interviewers were required to participate in additional training in remote surveying protocols.

NCI Year was included as a predictor primarily to account for COVID-related changes to interviewer training, methodology, and data collection.

Results

Research Question 1

Most participants reported high levels of privacy, ranging from 55.2% to 97.7% (see Table 3). The item *havephone* exhibited the lowest reported average level of reported privacy. In contrast, *bealone* exhibited the highest average, suggesting that the greatest number of participants had a place to be by themselves at home. The items *readmail* and *enterhome* had similarly large means, indicating that most participants reported others did not read their mail or email without permission and asked before entering their home.

When comparing responses across sample years (FY 2021–2023) using a chi-square test, we found no significant differences in participants' responses for the following items: *enterhome, enterbedroom, bealone, readmail, havephone,* and *lockbedroom* ($p > .05$). However, significant associations between sample year and privacy were found for *phonerules* ($\chi^2[2, N = 967] = 19.67$, $p < .001$) and *visitorrules* ($\chi^2[2, N = 858] = 20.94$, $p < .001$). Specifically, 51.57% of participants reported having rules about friends or visitors in their home in 2020–2021, compared to only 32.31% in 2022–2023.

The opposite trend was observed with phone and internet rules: 8.43% of participants reported having such rules in 2020–2021, compared to 20.65% in 2022–2023. These findings suggest that participants experienced fewer obstacles to their face-to-face interactions with visitors over time, but possiblity experienced more barriers to their communication privacy. Significant associations were also found between year and the items *keyhome* ($\chi^2[4, N = 2,175] = 46.45$, $p < .001$) and *stayhome* ($\chi^2[4, N = 2,021] = 39.60$, $p < .001$). From 2021 to 2023, participants consistently reported increases in having keys to their homes and being able to stay home when they wanted. These findings show that reported privacy continued to improve over time.

Research Question 2

Logistic regression models examined whether and to what extent personal characteristics predicted missing data (see Table 4). After controlling for other predictors, level of ID significantly predicted missingness across the majority of privacy items, including *enterhome, enterbedroom*, *bealone, readmail*, *visitorrules, phonerules, havephone, stayhome,* and *lockbedroom*. Only one item, *keyhome,* was not significantly predicted by level of ID.

Severe and profound ID predicted a greater likelihood of missingness for all items except for *stayhome* and *lockbedroom*. For most items, respondents with mild ID had the lowest rate of missing data (up to 29.4%), while people with profound ID had the highest (up to 96.8%). For the items *enterhome, enterbedroom, bealone, readmail, visitorrules, phonerules,* and *havephone*, the categorical shift from mild ID to moderate ID increased the odds of a missingness by at least 199% (*visitorrules)* and up to 278% (*havephone*). The categorical shift from moderate ID to severe ID increased the odds by as much as another 278%.

In some cases, such as with *stayhome*, the odds of missingness decreased among people with more severe levels of ID. For example, participants with moderate ID were 55% less likely to have a missing response than those with mild ID. Similarly, for *lockbedroom,* the item with the lowest reported privacy score, the odds of a missing response were 44% lower for someone with moderate ID compared to those with mild ID.

Preferred means of expression also significantly predicted missingness across the majority of privacy items, including *enterhome, enterbedroom, bealone, readmail, visitorrules,* *phonerules*, *havephone*, and *keyhome*. For two items, *stayhome* and *lockbedroom*, missingness was not significantly associated with preferred means of expression. Across the majority of these items, missing responses were lowest among those who preferred spoken communication (up to 35.5%). In contrast, those who preferred gestures for communication had the highest rate of missing data (up to 92.9%). Compared to those who preferred spoken communication, participants who preferred to communicate with gestures had odds of missingness that were at least 94% higher for *keyhome* and up to 397% higher for *readmail*.

Type of residence did not significantly predict missingness for any privacy items after controlling for participants' level of ID, preferred means of expression, and NCI-IPS sample year. However, sample year was a significant predictor of missingness for the item *phonerules*. Specifically, missingness for this item increased by 16% from sample year 2020–2021 to year 2021–2022.

Discussion

Privacy is highly valued by people with IDD and their supporters (Brand et al., 2020). This study examined privacy assessments by people with IDD. The results summarized opportunities and experiences of privacy, and described patterns of missingness for subpopulations that did not or could not assess their privacy using a broad set of NCI-IPS items.

On average, respondents described residential and service environments that extended the privacy expected by those with and without disabilities (Research Question 1). They reported having territorial privacy rights, evidenced by opportunities to lock bedroom doors, control who and could enter private spaces and when, and access to spaces where they could be alone when needed (see Table 3). The implication was twofold: respondents had spaces of their own and, broadly, others did not infringe on those spaces.

Territorial privacy had to be co-created by others sharing residential spaces, and privacy was reified each time permission was requested to enter a bedroom or when individual choices for solitary times and spaces were respected. Houseworth and colleagues (2019), in their analysis of approximately 10,000 NCI-IPS interview responses from 29 states, found similarly positive assessments of territorial privacy. They reported that close to 80% said that others had to give notice before entering bedrooms, and nearly 90% said they had enough privacy at home. Participants in this study reported even higher rates of people asking before entering personal spaces, and approximately 80% of respondents reported they could lock their bedroom door. These results indicate that some of the privacy standards set forth by the Settings Rule, such as the privacy of one's own physical space, are commonly honored over time and across states (Houseworth et al., 2019). Residential settings feel safer, less institutional, and more home-like when people have autonomy over their private spaces (Clement & Bigby, 2010; McCarron et al., 2019).

Communication privacy can also reduce stress and promote a sense of safety (Brand et al., 2020; Lord, 2007). It allows individuals to decide when intimate information becomes known by broader audiences. Three cohorts in this study described control over their mail, email, and phone usage and correspondence (see Table 3). Often, they chose who opened their mail and were extended the decisional authority over how they used their phones and internet—tools connecting them to others, information, and personal interests. This stands in contrast to violations of communication privacy, such as restrictions on internet and smartphone usage, which have been rationalized as risk reduction strategies (Livingstone et al., 2015). However, many people with IDD are aware of the risks presented in virtual environments, including various forms of internet-mediated communication (Seale & Chadwick, 2017). Furthermore, the freedom to privately access all forms of communication fosters continued participation, even when physical participation is difficult or temporarily disrupted (Wahl & Kuppis, 2023).

Most people who responded to survey questions reported experiencing both territorial and communication privacy. However, over the three years data were collected, six of the ten NCI-IPS privacy items selected for examination had missing responses from more than 50% of sample participants. More critically, people with IDD, families, and the systems that oversee HCBS supports and services, including those with broad acknowledgments of service users' right to privacy (Friedman, 2023), should be concerned that privacy assessments and experiences are unknown for such a broad group of HCBS service users, especially those labeled as having moderate, severe or profound ID.

Results of research question 2 showed that missing privacy responses for nine of the ten items were predicted by the severity of ID, specifically for people categorized as having moderate, severe, or profound ID. Furthermore, missing responses to eight of the ten privacy items were also significantly predicted by whether participants used non-verbal forms of communication, such as gestures, sign language, and communication devices. These missing data are problematic because populations with greater support needs are precisely those at risk for being overprotected and over-surveilled (Esteban et al., 2021). One study of over 20,000 participants with IDD from a national sample found that, compared to HCBS services users with mild ID, those more with more severe ID were significantly less likely to report basic privacy rights (authors, 2023). Moreover, if the presence of privacy is considered an indicator of community integration, then missing privacy data prevent systems from accessing key metrics needed for understanding the intended outcomes for service users with IDD.

The interaction between personal characteristics, such as level of ID, and NCI methodology may inadvertently suppress responses from people with greater support needs. Survey strategies like reverse phrasing, an increased number of response options, and reliance on scaled responses can increase the cognitive load on respondents, making participation more challenging for people with IDD (e.g., Nicolaidis et al., 2020). For example, results from this study showed that missingness in the privacy item *phonerules* was predicted by both level of ID and survey year. In the 2020–2021 survey, there were two primary response options, in addition to 'Not Applicable' and 'Don’t Know': either phone and internet rules were present or they were not. Starting in 2022, the number of response options doubled, as the affirmative response (“yes, there were phone and internet rules”) was split into three distinct options: “Rules about internet only,” “Rules about phone only,” and “Rules about using phone and internet.” This expansion in response options may have partially contributed to increased missingness, highlighting how methodological artifacts can significantly affect survey participation.

This study highlights both the challenges and opportunities of using the NCI-IPS to assess the privacy experiences of service users with IDD. It contributes to ongoing discussions about developing more inclusive survey and interview methods for people with IDD, particularly those with greater support needs. However, these efforts must be balanced with the practical demands faced by states in maintaining, utilizing, and responding to administrative data. Measurement tools and implementation protocols must not only be feasible and accessible to enable individuals with IDD to share their experiences, but also sustainable for service systems to collect and use this data effectively to improve privacy through supports and services.

Limitations

As of 2025, 48 states and the District of Columbia were participating in NCI-IPS data collection. Patterns of responses and missingness for selected privacy items may vary considerably across these states. Interviewers from each state are required to participate in survey administration training. However, the extent of additional interviewer training and monitoring varies by state, and despite training, there will always be a degree of inconsistency (i.e., error) in how trained interviewers act on unintelligible responses. It is realistic to expect that interpretations by trained interviewers contain embedded variability both within and across states. These and other differences in participant characteristics and service provision may limit the generalizability of privacy responses and missingness reported in this study.

HSRI’s annual NCI-IPS reports present opportunities to compare privacy items across states and against national benchmarks. Each state should examine predictors of missingness to determine whether survey administration could be meaningfully improved for specific subpopulations. Similarly, HSRI reports the percentage of invalid responses in NCI-IPS Section I across all states. Although personal characteristics (e.g., level of ID) predict missingness, states consistently exhibiting the greatest proportion of invalid responses may consider additional training opportunities for interviewers to improve the use of strategies such as rewording or rephrasing to maximize participation of those who do not communicate verbally or who only provide yes/no responses. NCI also permits states to develop items to add to the survey. Therefore, states interested in certain conceptualizations and operationalizations of privacy have opportunities to develop accessible items for participants with IDD. Finally, NCI could also consider revising items, response options, and protocols to better support people with the greatest support needs in sharing their experiences.

Another limitation was that the NCI-IPS includes a limited number of items used to measure “rights and privacy.” Beyond the identified “rights and privacy” section of the NCI-IPS, other items in the survey have been deemed applicable for describing privacy (e.g., Authors, 2022; Ticha et al., 2018; Houseworth et al., 2019). This study, like others, was limited to available NCI-IPS items, which may not encompass all possible elements of privacy generally and territorial or communication privacy more specifically.

Future Directions

To advance community integration and combat stigma, people with IDD need greater opportunities to access and control their privacy. This research describes positive privacy experiences among NCI-IPS respondents; however, in some cases, specific subpopulations of people with IDD have been identified as having less access to privacy, including adults under full guardianship and those with greater support needs (Authors, 2023; Brandt et al., 2020; Esteban et al., 2021; Houseworth et al., 2019). In each case, privacy has been conceptualized and operationalized differently. There is an opportunity to build and validate a privacy scale or multiple scales.

A barrier to developing a privacy scale using the NCI-IPS is high rates of missing and unknown responses, which make it difficult for measurement models to converge. Therefore, the methodological conversation must switch from whether privacy is present to an antecedent question: how can surveys and interviewers improve data collection methods and procedures to enhance privacy feedback for participants with greater support and communication needs? Failure to address this comes at the expense of supports and services users, because without meaningful metrics to assess privacy and privacy concerns, it is difficult to practically develop and implement training and interventions for providers and service systems.

Conclusion

Privacy allows individuals to withdraw from obligatory interactions and the sensory demands of the external world. It provides a controlled space for rest, reflection, and autonomy. For systems, however, privacy may serve as a right and a distinguishing factor of community integration. Privacy is individually, culturally, and politically important. Using available tools, many people describe elements of privacy as available and under their control. Still, efforts to conceptualize and accurately capture the presence or absence of privacy for ALL people with IDD remain insufficient.

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Table 1

Demographics of State National Core Indicators Samples From 2020-2021, 2021-2022, and 2022-2023

Demographics	Frequency			
	2020-2021	2021-2022	2022-2023	Full Sample
N	719	715	762	2196
Age	*M* = 41.55, *SD* = 16.00	*M* = 40.74, *SD* = 15.89	*M* = 40.61, *SD* = 15.55	*M* = 40.96, *SD* = 15.80
Gender				
Male	59%	62%	63%	61%
Female	41%	38%	37%	39%
Race				
American Indian/ Alaskan Native	<1%	< 1%	< 1%	<1%
Asian	3%	2%	3%	3%
Black/African-American	30%	31%	30%	30%
White	64%	62%	64%	63%
Latinx	3%	2%	3%	2%
Other	2%	2%	2%	2%
Don’t Know	< 1%	2%	2%	1%
Level of Intellectual Disability				

Mild	33%	32%	31%	32%
Moderate	38%	43%	43%	41%
Severe	19%	19%	16%	18%
Profound	10%	6%	10%	9%
Expression				
Spoken	74%	79%	74%	76%
Gestures	21%	17%	21%	20%
Sign Language	2%	2%	2%	2%
Communication Aid	3%	3%	3%	3%
Residence Type				
Independent Home or Apartment	8%	7%	9%	8%
Parent or Relative’s Home	30%	38%	39%	35%
Group Setting 2-3 Residents	9%	6%	8%	7%
Group Setting 4-6 Residents	31%	29%	26%	28%
Group Setting 7-15 Residents	5%	3%	3%	3%
Host Home	18%	18%	16%	18%

Table 2

Description of NCI-IPS Privacy Items and Aggregate Missingness for 2021-2023

	Privacy Items by NCI-IPS Section									
	Section I - Home			Section I - Rights and Privacy				Section II - Rights		
Item	enterbedroom	enterhome	bealone	readmail	visitorrules	phonerules	havephone	keyhome	stayhome	lockbedroom
Item Description	†Do people ask you before coming into your bedroom?	†Do people who do not live with you ask you before they come into your home?	Do you have a place to be alone in your home?	Do people read your mail or email without asking you first?	Are there rules about having friends or visitors in your home?	†Are there rules about using phone or internet?	Do you have a cell phone or smart phone?	†Do you have a key to your home?	When people in your house go somewhere, do you have to go too, or can you stay at home if you want to?	†Can you lock your bedroom if you want to?
Response Options	1- No 2- Sometimes 3- Yes	1- No 2- Sometimes 3- Yes	1- No 2- Yes	1- Yes, mail/email is read without permission 2- No, person reads own mail/email or others read with permission	1- There are rules against having friends or visitors in the home 2- No rules about having friends or visitors in the home	1- Rules about using phone and internet 2- No rules about using phone or internet	1- No 2- Yes	1- No 2- Maybe, not sure 3- Yes	1- No, always has to go 2- Sometimes can stay at home; sometimes has to go 3- Yes, can stay at home	1- No 2- Maybe, not sure 3- Yes

Percent Missingness	*50.32%	*52.60%	48.77%	*56.15%	*60.93%	*55.97%	*50.32%	0.96%	7.97%	7.06%

Note. For all items, participants had the option to respond “Not applicable” or “Don’t know/no response/unclear response”, which were treated as missing responses; * items exhibited over 50% missingness. ǂitem wording and/or wording of response options changed across sample years.

Table 3

Frequencies of Privacy Items

	Frequencies			
Privacy Item	2020-2021	2021-2022	2022-2023	Full Sample
enterbedroom	No = 6.69% Sometimes = 6.96% Yes = 86.35%	No = 8.29% Sometimes = 8.02% Yes = 83.69%	No = 6.70% Sometimes = 4.75% Yes = 88.55%	No = 7.24% Sometimes = 6.60% Yes = 86.16%
enterhome	No = 2.93% Sometimes = 3.52% Yes = 93.55%	No = 4.83% Sometimes = 4.55% Yes = 90.63%	No = 4.02% Sometimes = 3.74% Yes = 92.24%	No = 3.94% Sometimes = 3.94% Yes = 92.12%
bealone	No = 2.45% Yes = 97.55%	No = 2.02% Yes = 97.98%	No = 2.49% Yes = 97.51%	No = 2.31% Yes = 97.69%
*readmail	Yes = 8.17% No = 91.83%	Yes = 8.61% No = 91.39%	Yes = 12.50% No = 87.50%	Yes = 9.76% No = 90.24%
*visitorrules	Yes = 51.57% No = 48.42%	Yes = 42.58% No = 57.42%	Yes = 32.31% No = 67.69%	Yes = 41.72% No = 58.28%
*phonerules	Yes = 8.43% No = 91.57%	Yes = 16.92% No = 83.08%	Yes = 20.65% No = 79.35%	Yes = 15.20% No = 84.80%
havephone	No = 46.98% Yes = 53.02%	No = 45.48% Yes = 54.52%	Yes = 41.88% No = 58.12%	No = 44.82% Yes = 55.18%
keyhome	No = 30.43% Maybe = 0.42% Yes = 69.14%	No = 29.46% Maybe = 0.14% Yes = 70.40%	No = 16.80% Maybe = 0.53% Yes = 82.67%	No = 25.38% Maybe = 0.37% Yes = 74.25%
stayhome	No = 23.66% Sometimes = 14.73% Yes = 61.61%	No = 13.98% Sometimes = 21.20% Yes = 64.82%	No = 12.75% Sometimes = 21.06% Yes = 66.19%	No = 16.77% Sometimes = 19.00% Yes = 64.23%
lockbedroom	No = 19.21% Maybe = 2.05% Yes = 78.74%	No = 19.03% Maybe = 0.91% Yes = 80.06%	No = 14.96% Maybe = 1.42% Yes = 83.62%	No = 17.69% Maybe = 1.47% Yes = 80.84%

Note. * = reverse coded

Table 4

Multinomial Logistic Regression Analysis Showing Association Between Predictors and Missingness

			95% CI for odds ratio		
Outcome Variable	*b*	*SE*	Lower	Odds Ratio	Upper
enterbedroom					
Level of ID	1.26**	0.08	2.99	3.52	4.16
Expression	1.08**	0.14	2.28	2.95	3.89
Residence Type	0.04	0.03	0.99	1.06	1.11
Sample Year	0.05	0.07	0.91	1.05	1.20
enterhome					
Level of ID	1.24**	0.09	2.93	3.46	4.12
Expression	1.40**	0.16	2.99	4.06	5.66
Residence Type	0.02	0.03	0.96	1.02	1.08
Sample Year	0.02	0.07	0.89	1.02	1.18
bealone					
Level of ID	1.22**	0.08	2.88	3.38	4.00
Expression	1.08**	0.13	2.30	2.94	3.84
Residence Type	0.01	0.03	0.95	1.01	1.07

Sample Year	0.09	0.07	0.95	1.09	1.25
readmail					
Level of ID	1.20**	0.09	2.81	3.32	3.96
Expression	1.60**	0.19	3.50	4.97	7.36
Residence Type	-0.03	0.03	0.91	0.97	1.03
Sample Year	-0.03	0.07	0.84	0.97	1.12
visitorrules					
Level of ID	1.10**	0.09	2.53	2.99	3.56
Expression	1.43**	0.19	2.92	4.17	6.22
Residence Type	-0.04	0.03	0.91	0.96	1.02
Sample Year	-0.09	0.07	0.80	0.92	1.05
phonerules					
Level of ID	1.28**	0.09	3.03	3.59	4.29
Expression	1.40**	0.18	2.94	4.07	5.84
Residence Type	-0.02	0.03	0.93	0.98	1.04
Sample Year	0.15*	0.07	1.01	1.16	1.34
havephone					
Level of ID	1.33**	0.09	3.19	3.78	4.50
Expression	1.24**	0.15	2.62	3.45	4.66

Residence Type	0.00	0.03	0.95	1.00	1.07
Sample Year	0.12	0.07	0.98	1.12	1.30
keyhome					
Level of ID	-0.06	0.29	0.52	0.94	1.65
Expression	0.66*	0.28	1.05	1.94	3.23
Residence Type	0.02	0.14	0.78	1.02	1.34
Sample Year	-0.18	0.32	0.44	0.83	1.55
stayhome					
Level of ID	-0.79**	0.15	0.34	0.45	0.60
Expression	-0.11	0.21	0.57	0.90	1.29
Residence Type	0.05	0.05	0.95	1.05	1.16
Sample Year	0.02	0.12	0.81	1.02	1.29
lockbedroom					
Level of ID	-0.57**	0.15	0.42	0.56	0.75
Expression	0.13	0.18	0.78	1.14	1.57
Residence Type	0.05	0.05	0.94	1.05	1.17
Sample Year	0.08	0.13	0.85	1.09	1.40

Note. ID = Intellectual Disability. **p* < .05, **p < .01.