

**Assessment of Illinois Home and Community Based Services
Agencies Providing Non-Residential Services**

Developed to assist the Illinois Statewide Transition Plan

Conducted by the Survey Research Office, Center for State Policy & Leadership,
University of Illinois Springfield

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Introduction

The purpose of this study is to examine the policies, procedures, and activities of non-residential settings for Home or Community Based Service waivers. In order to accomplish this, the UIS Survey Research Office, Center for State Policy & Leadership, used a multi-mode methodology in order to allow agencies and settings to self-report on the types of policies and procedures in place throughout settings in Illinois. This report contains four chapters in addition to this introduction.

1. **Scope of Project-** This section provides a brief introduction to the Centers for Medicare and Medicaid Services' (CMS) final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings.
2. **Summary of Results-** The purpose of this section is to summarize the results of the two surveys as well as provide an overview of the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.” These scores are the numerical values that will be used to identify the key areas of the Illinois Statewide Transition Plan. This section contains four subsections:
 - a. Results from the Agency-Specific Surveys
 - b. Characteristics of the Non-Residential Settings
 - c. Individuals’ Access to the Community in Non-Residential Settings
 - d. Individuals’ Personal Choice in Care Options in Non-Residential Settings.
3. **Methodology-** This section provides a detailed analysis of the methodological design of this project. There were systematic decisions on how to assess all aspects of the settings from engagement with the community, transportation opportunities, dining and meal accommodations, and personal autonomy and choice in care options. A detailed discussion of these decisions and the methodology employed by UIS researchers is provided in the methodology section.
4. **Survey Report-** This is a topline report which includes complete question wording and the frequency of responses to each of the answer categories.

Scope of Project

The Centers for Medicare and Medicaid Services (CMS) published its final rule relating to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings. The final rule took effect on March 17, 2014. According to this rule, states are required to submit transition plans to CMS within one year of the effective date indicating how they intend to comply with the new requirements within a reasonable time period.

In an effort to follow the CMS final rule guidance, the Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging, developed several surveys with assistance of researchers from the UIS Survey Research Office in order to assess the State's current compliance with the new regulations specific to the residential and non-residential settings requirements. This report deals specifically with non-residential settings offered through HCBS waivers.

The following Illinois HCBS waivers are included in this analysis:

- Children and Young Adults with Developmental Disabilities
- Children that are Technology Dependent/Medically Fragile
- Persons with Disabilities
- Persons with Brain Injuries (BI)
- Adults with Developmental Disabilities
- Persons who are Elderly
- Persons with HIV or AIDs
- Supportive Living Facilities

The following types of settings are **not** included in this classification:

- Hospitals
- Institutions for mental diseases
- An *intermediate* care facility for individuals with intellectual disabilities
- Nursing facilities
- Mental health or DASA residential sites
- Residences for private pay residents only
- Individuals receiving care in their private residences/family homes

This report provides the results of the examination of non-residential settings for Illinois HCBS waivers.

Summary of Results

The results chapter contains four main sections: Results from the Agency-Specific Surveys, Characteristics of the Non-Residential Settings, Individuals' Access to the Community in Non-Residential Settings, and Individuals' Personal Choice in Care Options in Non-Residential Settings. This executive summary provides an overview of each of the sections as well as a synopsis of the findings. It also provides an overview of the “Level of Autonomy Score” and a “Frequency of Independent Behaviors Score.” These scores are the numerical values that will be used to identify the next steps as part of the Illinois Statewide Transition Plan.

Results from the Agency-Specific Surveys

The main survey required from each agency which operates at least one non-residential setting in Illinois was titled the “Agency-specific survey.” Agencies were able to complete this survey online, paper copies sent via U.S. mail, or over the phone with trained SRO interviewers. Of the 218 agencies operating at least one non-residential setting for Illinois waiver HCBS participants, 214 completed the agency-specific form. This resulted in a 98 percent completion rate among all agencies. The agencies that did not complete the agency-specific form will be contacted by their corresponding state agency in early 2015 in order to assess whether or not these agencies operate non-residential settings in Illinois. Those that do will be required to complete the agency-specific survey with an individual from the corresponding state agency (Illinois Departments of Healthcare and Family Services, Human Services, or Aging).

There are two main purposes of the agency-specific survey:

- 1) Determine the number of non-residential settings in Illinois for HCBS waivers;
- 2) Identify the agencies that have agency-wide policies and procedures that regulate various aspects of the daily operations of their settings.

The main findings of the agency-specific survey are listed below:

- There are currently 459 non-residential settings in Illinois.
- The majority of agencies have agency-wide policies that apply to the setting(s) regarding three issues: (a) visitation procedures, (b) right to privacy, and (c) community integration.
- The majority of agencies do not have agency-wide policies that limit the setting(s) for the following: (a) staff-individual interaction, (b) community engagement, and (c) engaging in legal activities. For the frequency of responses to these questions, please see the topline report at the end of this report.
- Eighty percent of settings have policies to support access to the greater community.
- Ninety percent of settings have policies that facilitate individual choices in care and services.
- Ninety-four percent of settings have policies that ensure individual privacy.
- Ninety-five percent of settings are physically accessible to the majority of individuals.

Characteristics of the Non-Residential Settings

The setting-specific survey completed by 409 non-residential settings allows researchers to gain unique insight into the demographic characteristics of the non-residential settings. The demographic section provides three important pieces of information.

- 1) The number of individuals (both Illinois HCBS waivers and others) at each non-residential setting.
- 2) The physical location and type of building of each setting.
- 3) The controlling entity for each of the settings.

Number of individuals

The average number of waiver participants supported at each setting is 79, with 90 percent of the setting supporting fewer than 150 individuals.. This is out of an average number of 163 total individuals (waiver and non-waiver participants) at the non-residential settings.

Physical location and type of building

- Six settings (1.5%) report that they are “physically connected to a hospital, nursing facility, institution for mental disease, or an intermediate care facility for individuals with intellectual disabilities.”
- Twenty-eight (6.9%) report that while they are not physically connected, they are on the grounds or adjacent to these types of facilities.
- The majority (91.6%) report that they are not physically connect nor adjacent to these type of facilities.

When we examine types of settings, we find that the majority of respondents are Developmental Training settings with 68.7 percent reporting that this describes their setting.

Table 1. Types of settings

	Percent (<i>n</i>)
Adult Day Care	16.9% (69)
Adult Day Health Services	3.9% (16)
Developmental Training	68.7% (281)
Prevocational Services (services provided under the brain injury waiver)	0.2% (1)
Supported Employment	5.1% (21)

When asked to describe this setting as located in a rural area (located outside of a metropolitan area), located in a suburban area, or located in an urban area, respondents were split evenly across all three categories. As seen in the table below, a slightly higher percentage reported being in a rural areas, 37.8 percent compared to 34.3 percent who reported being in a suburban area, and 34.3 percent who reported being in an urban area.

Table 2. Description of settings

	Percent (<i>n</i>)
Located in a rural area (located outside of a metropolitan area)	37.8% (153)
Located in a suburban area	34.3% (139)
Located in an urban area	27.9% (113)

When asked to describe the setting, the majority described it as a stand-alone building located on a public street or highway. Table 3 provides the complete list.

Table 3. Physical description of settings

	Percent (<i>n</i>)
Multiple settings co-located/campus	14.2% (58)
A gated/secured community	1.2% (5)
Stand-alone building located on a public street or highway	84.6% (346)
Hospital	0.5% (2)
Nursing homes	0.7% (3)

Controlling Entity

In addition, when asked what entity or entities control(s) the policies or procedures for the setting, 84 percent report that it is the parent agency or organization. Eleven percent report that the individual setting controls the policies or procedures (46), followed by a subsidiary or foundation (0.2%).

Finally, settings were told to identify all of the state agencies from which they receive funding for their services. As seen in the table below, the Illinois Department of Human Services is the largest funder for services.

Table 4. State Agency Funding Services

	Number of settings
Illinois Department of Healthcare and Family Services	115
Illinois Department of Human Services Division of Developmental Disabilities	335
Illinois Department of Human Services Division of Rehabilitation Services	77
Illinois Department on Aging	152

The final two results sections discuss the results of the setting-specific survey. The setting-specific survey deals with all aspects of the non-residential settings. In order to reduce the complexity of this instrument, we have categorized these into two factors: Individual's Access to the Community in Non-Residential Settings and Individuals' Personal Autonomy and Choice in Care Options in Non-Residential Settings. Each of these sections has the following subsections.

Individuals' Access to the Community in Non-Residential Settings

- Community Engagement

- Transportation Opportunities

Individuals’ Personal Choice in Care Options in Non-Residential Settings

- Individual Care Plans
- Setting Accommodations

Each of settings receives two scores within each of the four subsections: a “Level of Autonomy Score” and a “Frequency of Independent Behaviors Score.” These scores measure related but unique concepts. The “Level of Autonomy Score” measures what level of autonomy or personal freedom individuals experience based on the policies of each non-residential setting. The “Frequency of Independent Behaviors Score” measures how often individuals engage in these autonomous behaviors. These scores are calculated similarly among all of the four subsections.

“Level of Autonomy Score”- This score is calculated using items on a five-point Likert scale ranging from “Strongly Agree (5), Somewhat Agree (4), Neither Agree nor Disagree (3), Somewhat Disagree (2), Strongly Agree (1).” Settings were asked to report their level of agreement on a variety of different items measuring each of the four subsections. For example, one of the items measuring community engagement using the Likert scale asked respondents their level of agreement with the following statement: *Individuals are given easy access to the community outside of the setting.* While each of the subsections may have a different number of items measuring the concept, the “Level of Autonomy Scores” are standardized.

The scores for each of the subsections range from 1 to 5, where 1 indicates the lowest level of autonomy and 5 indicates the highest level of autonomy. The table below provides the mean “Level of Autonomy Score” for each of the subsections with the standard deviations in parentheses.

Table 5. Level of Autonomy Scores

	Level of Autonomy Score
Community Engagement	3.76 (.64)
Transportation Opportunities	3.84 (.67)
Individual Care Plans	3.78 (.59)
Setting Accommodations	3.79 (.40)

As seen in the table above, all of the “Level of Autonomy Scores” range between the neutral category (3: Neither Agree nor Disagree”) and the strong agreement category (5: “Strongly Agree”). Overall, this indicates a high level of autonomy in each of the four subsections. Transportation Opportunities has the highest “Level of Autonomy Score” while Community Engagement has the lowest “Level of Autonomy Score.” To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

“Frequency of Independent Behaviors Score”- This score is calculated using a four-point frequency measure ranging from “All of the time” (4), “Most of the time” (3), “Some of the time” (2), “Never” (1). Settings were asked to report how often a variety of different behaviors occurs for each of the four subsections. For example, one of the items measuring individual care plans using the frequency scale asks respondents to report the frequency of the following item: *Individuals’ complaints are addressed in a timely manner.*

The scores for each of the subsections range from 1 to 4, where 1 indicates the lowest frequency amount and 4 indicates the highest frequency amount. The table below provides the mean “Frequency of Independent Behaviors Score” for each of the subsections with the standard deviations in parentheses.

Table 6. Frequency of Independent Behaviors Score

	Frequency of Independent Behaviors Score
Community Engagement	2.85 (.69)
Transportation Opportunities	3.47 (.56)
Individual Care Plans	3.31 (.31)
Setting Accommodations	3.07 (.73)

As seen in the table above, all of the “Frequency of Independent Behaviors Scores” range between “Some of the Time” (2) and “All of the Time” (4). Individual Care Plans has the highest “Frequency of Independent Behaviors Score” at 3.31. This indicates that when it comes to individuals’ care plans, the majority of individuals are able to assert a high level of independent behavior. The lowest “Frequency of Independent Behaviors Score” is Community Engagement with 2.85. To find a detailed discussion of the items that constructed each of these scores, please see the corresponding section in the following pages.

The following pages discuss the four subsections of the results section. Each of the sections provides an overview of the findings (bullet points), and detailed descriptions of both the “Level of Autonomy Score” and the “Frequency of Independent Behaviors Score.”

Individuals’ Access to the Community in Non-Residential Settings

This results section is concerned with the policies and procedures in place that allow individuals to be able to access the external community, outside of the non-residential setting. This section contains two subsections: Community Engagement and Transportation Opportunities.

Community Engagement

- Overall, community engagement within the nonresidential settings scored the lowest on both the measure of Level of Autonomy as well as the Frequency of Independent Behaviors.
- Slightly more than half of non-residential settings report that individuals regularly engage in community activities while at the setting (55.3 percent), compared to 35.5 percent who report that individuals engage occasionally, and 9.2 percent who report that the individuals do not participate often.
- Sixty-percent of non-residential settings report that helping individuals obtain integrated employment opportunities is part of their service.
- The overall “Level of Autonomy Score” for community engagement is 3.76 (out of 5); The “Frequency of Independent Behaviors Score” for community engagement is 2.85 (out of 4).

The overall “Level of Autonomy Score” for community engagement is 3.76, which indicates a lower level of autonomy for participants in terms of their engagement in the community. When we examine the six items that constructed this score, we find slight differences among the different measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). The item that had the highest percent of respondents reporting that a low autonomy score is “Participants are able to come and go as they please.” One-fourth of settings reported that this was not true at their setting.

Table 7. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Participants are able to come and go as they please.	25.1%
Participants know where to find information on community activities.	3.3%
Participants are given easy access to the community outside of the setting.	4.8%

The “Frequency of Independent Behaviors Score” was constructed using six items listed in the table below. The overall score for community engagement is 2.85, which indicates the lowest level of the frequency of independent behaviors. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “participants and community members interact at the setting.” However, fewer than 10 percent reported a “never” for all of these items.

Table 8. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Participants and community members interact at the setting.	5.8%
Participants pursue integrated/competitive employment opportunities.	5.6%
Participants pursue other employment opportunities (both paid and volunteer).	4.8%
Participants have the opportunity to engage in community activities while at the setting (both at the setting and in the community).	3.0%
Individuals pursue competitive employment opportunities.	3.0%
Interested participants are given the resources on how to obtain employment.	2.8%
Participants talk about community activities occurring outside of the setting.	1.5%

Transportation Opportunities

- Overall, transportation opportunities (both in terms of level of autonomy and frequency of independent behaviors) received the highest evaluation by non-residential settings.
- Eighty-three percent of non-residential settings report that there are retail businesses near their setting.
- Ninety percent of non-residential settings provide regularly-scheduled transportation opportunities to participants.
- The overall “Level of Autonomy Score” for transportation opportunities is 3.84; the “Frequency of Independent Behaviors Score” for transportation opportunities is 3.47.

The overall “Level of Autonomy Score” for transportation opportunities is 3.84, which indicates a high level of autonomy for participants in terms of their transportation opportunities. When we examine the four items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates a low level of autonomy). As you see in the table, the item that had the highest percent of respondents reporting a low autonomy score is “transportation opportunities are not limited for participants.”

Table 9. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
There are public transportation opportunities available to participants in the setting.	8.9%
The setting provides transportation opportunities to participants outside of regularly scheduled options.	12.7%
Transportation opportunities are not limited for participants.	15.9%
Participants feel confident using the transportation opportunities provided by the setting.	1.1%

The “Frequency of Independent Behaviors Score” was constructed using three items listed in the table below. The overall score for transportation opportunities is 3.475, which indicates a high level of the frequency of independent behaviors in terms of transportation opportunities. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). As you can see in the table, the item that had the highest percent of respondents reporting a low frequency score is “participants are informed/educated on how to use public transportation.” Yet, less than 3 percent of non-residential settings reported that this “never” happens.

Table 10. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Participants are informed/educated on how to use public transportation.	2.5%
Participants use the transportation opportunities provided by the setting.	0.3%
Participants know how to contact a staff member about transportation opportunities.	1.6%

Participants’ Personal Choice in Care Options in Non-Residential Settings

This results section is concerned about the level of personal choice individual participants have while attending the settings. This includes their individual care plans, their sense of individuality, their dining arrangements, and their interactions with visitors and staff members. This section contains two subsections: Individual Care Plans and Setting Accommodations.

Individual Care Plans

- A vital component of the new federal regulations is that participants at non-residential settings have flexibility and freedom in developing their individual care plans. The results of this survey indicate that the frequency of independent behaviors associated with individual care plans is at a moderate level.
- The majority of the non-residential settings that responded to this survey report that participants have a lot of choice.
- Almost all of the settings (97%) report that the average individual at their setting has been asked about their goals and aspirations in the past 12 months and 69.7 percent report that participants make changes to their plan of care “as needed or as requested.”
- The overall “Level of Autonomy Score” for individual care plans is 3.78, the “Frequency of Independent Behaviors Score” for individual care plans is 3.31.

The overall “Level of Autonomy Score” for individual care plans is 3.78, which indicates a moderate level of autonomy for participants in terms of their individual care plans. When we examine the six items that constructed this score, we find slight differences among the measures. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “Participants’ requests regarding their care are forward to an independent/non-setting based case manager.”

Table 11. Items of “Level of Autonomy Score”

	Percent reporting lowest rating of autonomy
Participants feel comfortable expressing concerns regarding their care.	1.0%
Participants know how make changes to their plans of care.	0.8%
Information on how to file a complaint is easily accessible to participants.	5.5%
Participants have a choice of which provider staff delivers care/support.	4.5
Participants’ requests regarding their care are forwarded to an independent/non-setting based case manager.	13.9%
Schedules for PT, OT, medication, diet, or other care options are NOT posted in common areas (i.e., hallways).	7.3%

The “Frequency of Independent Behaviors Score” was constructed using eight items listed in the table below. The overall score for individual care plan is 3.31, which indicates the high level of the frequency of independent behaviors in terms of individual care planning. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score). The item that had the highest percent of respondents reporting a low frequency score is “Staff members do not discuss participants with other staff members in public spaces.” 7 percent of settings reporting that this never happens.

Table 12. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
Individual complaints are addressed in a timely manner.	0.0%
Participants make changes to their plan of care as needed.	2.6%
Participants with concerns, discuss the concerns with the setting staff.	0.8%
Participants provide input into their daily schedules.	1.0%
Staff members do not discuss participants with other staff members in public spaces.	7.1%
When an individual files a complaint, it is considered confidential.	0.3%
When needed, participants know how to request a new/additional service.	1.3%
Participants have the opportunity to express their level of satisfaction with the services they are receiving.	0.0%

Setting Accommodations

- One way that participants are able to express their own personal choice is in their dining and meal decisions. According to the survey results, only 35.6 percent of non-residential settings provide or arrange for meals and food for participants while at the setting. Of those, only one-fourth report that the individuals have a lot of choice when it comes to dining/food options.
- According to the survey results, participants have a moderate level of autonomy when it comes to their setting accommodations as well as demonstrate a moderate amount of independent behaviors.
- The overall “Level of Autonomy Score” for setting accommodations is 3.80; the “Frequency of Independent Behaviors Score” is 3.07.

The overall “Level of Autonomy Score” for setting accommodations is 3.80. When we examine the ten items that constructed this score, we find slight differences among the items. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the lowest level of autonomy). The item that had the highest percent of respondents reporting the lowest autonomy score is “Participants are able to set their own dining/meal-time schedules.”

Table 13. Items of “Level of Autonomy Score”

	Percent
Persons without disabilities (other than staff members) engage with the participants at the setting.	6.2%
Community members are allowed to visit the setting at any time.	2.0%
Participants at the setting use a common entrance.	7.7%
The setting is not located in the same physical structure where individuals live or are treated on a permanent or temporary basis.	4.4%
Participants are free to move about public areas within the setting.	1.2%
Community members come to the setting to discuss external community activities.	11.2%
Participants have the opportunity to access areas that provide privacy while at the setting (excluding restroom facilities).	2.2%
Participants are not assigned seating during meal-times.	3.4%
Participants are able to set their own dining/meal-time schedules.	32.8%
Participants engage with others during meal-times.	1.6%

The “Frequency of Independent Behaviors Score” was constructed using two items listed in the table below. It is important to note that this only applies to the 143 non-residential settings that provide food or meal accommodations. The overall score is 3.07, which indicates a moderate level of the frequency of independent behaviors in terms for setting accommodations. The table below presents the percent of respondents who self-reported a “1” on this item (which indicates the survey response of “never,” the lowest frequency score).

Table 14. Items of “Frequency of Independent Behaviors Score”

	Percent reporting lowest level of frequency
There is more than one meal option during meal-times.	11.9%
Between designated meal-times, the setting provides other food or refreshments.	6.3%

Methodology

The HCBS non-residential survey is actually two surveys: an agency-specific survey and a setting-specific survey. Every agency was required to fill out both an agency-specific non-residential survey as well as a setting-specific non-residential survey for each of their non-residential settings. Settings were able to participate in the surveys via online, mail, and phone.

The Illinois Department of Healthcare and Family Services, along with the Department of Human Services and the Department on Aging provided a list of agencies which operate non-residential settings offered through HCBS waivers. A total of 218 agencies met these guidelines. Mailing addresses, contact information for the director of each agency, and email addresses were provided by each of the corresponding state agencies. All agencies were contacted at least five times by researchers at the Survey Research Office (SRO).

The first contact to the agencies was through emails from their corresponding state agencies: Illinois Departments of Healthcare and Family Services, Human Services, or Aging. After the email distribution, the same information was sent from the SRO in an introductory letter via U.S. Postal Service on October 17, 2014. This correspondence discussed the need for Illinois to take inventory of all supportive congregate and/or group non-residential settings that are not hospitals, nursing homes, IMDs or ICF-DDs. This letter also informed the agency that they will be receiving information on how to complete a survey for their non-residential settings from the University of Illinois at Springfield (UIS). In addition, the recipients received specific language explaining that while there are no right or wrong answers to questions, their participation in the survey is mandatory.

The first round of survey instruments was sent to each of the 218 agencies via U.S. Postal Service on October 31st, 2014. Included in the mailing was an introductory letter to the director of the agency, an agency-specific survey, six copies of the setting-specific survey, and five business reply envelopes. The agency-specific survey contained an identifying tracking number in order for SRO researchers to keep track of the agencies who had completed the surveys. Settings were instructed that they could complete the hard copies of the surveys included in the mailing packet or complete the surveys online through provided URLs. If agencies needed additional copies of the setting-specific survey, they were instructed to contact the SRO via email or telephone.

A reminder postcard was sent to all of the agencies on November 13th, 2014. This postcard contained the project identification number for each of the agencies as well the URL to complete the surveys online. A second mailing occurred on November 21st, 2014. This mailing included the introductory letter, the agency-specific survey, and one copy of the setting-specific survey. Agencies that had not completed the surveys by January 5th, 2015 received phone calls from trained SRO interviewers. These phone calls were placed at different dates and times of the work week in an effort to increase the number of responses. Phone interviews concluded on January 16, 2015. The survey closed on January 20, 2015.

Through these various methods, SRO was able to get information through the survey from 214 of the 218 agencies (93.6%) that operate non-residential settings in Illinois. In addition, these agencies are responsible for operating 409 non-residential settings in Illinois.

Response bias may occur within surveys that rely on self-assessment, especially in situations in which funding may be in jeopardy. The following steps were taken to mitigate this bias:

1) The instructions attached to both surveys -- agency-specific and setting-specific -- emphasized that the data provided by both the agency and the setting are for informational purposes only and will not be used to assess the federal compliance of either the agency or the setting.

2) The following information was included on every page of the setting-specific survey:

REMINDER: The input you provide will be used to inform the Transition Plan and will NOT be used to evaluate whether the setting is currently in compliance with the new federal requirements. For example, selecting “Never” or “Strongly Disagree” for one of the items does not indicate that you are not in compliance. *Please answer the questions based on what “typically occurs” in the setting.* The emphasis is on what are in the setting’s policies and procedures. It is recognized that individual’s plans of care may dictate certain restrictions that would be documented to cause harm or reflect one’s abilities.

3) The majority of both surveys used Likert scales to effectively evaluate agencies and settings. The Likert technique is one of the most used and most validated survey designs. It involves asking a respondent to indicate how much he/she agrees or disagrees with each of a set of statements. The surveys used a five-point Likert response scale: strongly disagree, disagree, neutral, agree, strongly agree.

4) Each survey included both positive statements (Participants have access to a kitchen setting.) and negative statements. (Participants do NOT have access to do their own laundry.) When a survey or section of a survey contains only positive or only negative items, research shows that this can influence how people respond. A set of items worded only positively (with no negative items mixed in) can induce a positive bias from respondents. They respond by agreeing with those items more than they might if the set also included negatively worded items. The same goes for only framing survey items negatively. Thus, to reduce this bias, the surveys always include a mix of positively and negatively worded items.

5) In addition to the Likert design, the survey included questions on the frequency of certain behaviors, rather than just asking whether the behavior occurs or not. The questions included asking respondents “how often” certain activities occur at the setting. The four-point response categories ranged from “all of the time,” “most of the time,” “some of the time,” and “never.” Including this scale allows participants to provide more specific and useful information.

The following report is separated into four sections: Results from the Agency-specific Surveys, Demographics of the Non-Residential Settings, Participants’ Access to the Community in Non-Residential Settings, Participants’ Personal Autonomy and Choice in Care Options in Non-Residential Settings.

If you have any questions or comments about this report, please contact the Survey Research Office:

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Topline Report

Agency-Specific Surveys

How much, if at all, do you agree with the following statements about your agency? Do you strongly agree, somewhat agree, somewhat disagree, or strongly disagree? If you do not know the answer, please check “Don’t know.”

There are agency-wide policies that apply to the setting(s) regarding visitation from community members, this refers to participants who are not currently being treated by the setting.

	Percent (<i>n</i>)
Strongly agree	49.0% (96)
Somewhat agree	29.6% (58)
Somewhat disagree	7.7% (15)
Strongly disagree	9.7% (19)
Don’t know	4.1% (8)

There are agency-wide policies and procedures that disallow participants from engaging in legal activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	11.2% (22)
Somewhat agree	7.7% (15)
Somewhat disagree	11.7% (23)
Strongly disagree	51.0% (100)
Don’t know	18.4% (36)

There are agency-wide policies and procedures that disallow participants from engaging in community activities at its setting(s).

	Percent (<i>n</i>)
Strongly agree	3.1% (6)
Somewhat agree	3.6% (7)
Somewhat disagree	8.7% (17)
Strongly disagree	79.1% (155)
Don’t know	5.6% (11)

There are agency-wide policies and procedures that limit individual interaction with staff members at the setting(s).

	Percent (<i>n</i>)
Strongly agree	4.1% (8)
Somewhat agree	7.2% (14)
Somewhat disagree	7.7% (15)
Strongly disagree	80.0% (156)
Don’t know	1.0% (2)

There are agency-wide policies and procedures that ensure an individual’s right to privacy.

	Percent (<i>n</i>)
Strongly agree	97.5% (193)
Somewhat agree	2.0% (4)
Somewhat disagree	0% (0)
Strongly disagree	0.5% (1)
Don’t know	0% (0)

There are agency-wide policies and procedures that ensure that the setting(s) are integrated in the community.

	Percent (<i>n</i>)
Strongly agree	59.7% (117)
Somewhat agree	33.7% (66)
Somewhat disagree	2.6% (5)
Strongly disagree	1.5% (3)
Don’t know	2.6% (5)

Please answer whether the following apply to all of your settings, some of your settings, none of your settings. If you do not know the answer, please check “Don’t know.”

There are policies to support access to the greater community at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	79.7% (157)
Applies to some of our settings	11.2% (22)
Applies to none of our settings	4.1% (8)
Don’t know	5.1% (10)

There are policies that facilitate individual choice in types of services provided to the individual at the setting.

	Percent (<i>n</i>)
Applies to all of our settings	90.9% (180)
Applies to some of our settings	5.6% (11)
Applies to none of our settings	3.5% (7)
Don’t know	0% (0)

The setting is physically accessible to the majority of participants.

	Percent (<i>n</i>)
Applies to all of our settings	94.4% (187)
Applies to some of our settings	5.6% (11)
Applies to none of our settings	0% (0)
Don’t know	0% (0)

There are policies that ensure participants have privacy while at the setting(s).

	Percent (<i>n</i>)
Applies to all of our settings	93.9% (186)
Applies to some of our settings	3.5% (7)
Applies to none of our settings	1.5% (3)
Don't know	1.0% (2)

Setting-Specific Survey

How many HCBS or other State-funded approved participants are supported at this location?

	Percent (<i>n</i>)
Less than five	9.5% (37)
Five to 10 participants	4.6% (18)
11-20 participants	12.6% (53)
21-50 participants	27.6% (116)
More than 50 participants	45.7% (185)

Out of how many total participants?

	Percent (<i>n</i>)
Less than five	1.3% (5)
Five to 10 participants	4.3% (11)
11-20 participants	8.3% (20)
21-50 participants	33.1% (88)
More than 50 participants	53.0% (285)

Which of the following best describes your setting?

	Percent (<i>n</i>)
Physically connected to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	1.5% (6)
Not physically connected but on the grounds or adjacent to a hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	6.9% (28)
Not physically connected or adjacent hospital, nursing facility, institution for mental diseases, or an intermediate care facility for participants with intellectual disabilities.	91.6% (373)

Please identify all state agencies with whom you may receive funding to provide services for:

	Percent (n)
Illinois Department of Healthcare and Family Services	28.1% (115)
Illinois Department of Human Services Division of Developmental Disabilities	81.9% (335)
Illinois Department of Human Services Division of Rehabilitation Services	37.2% (77)
Illinois Department on Aging	18.8% (152)

Which of the following best describes the setting?

	Percent (n)
Adult Day Care	16.9% (69)
Adult Day Health Services	3.9% (16)
Developmental Training	68.7% (281)
Prevocational Services (services provided under the brain injury waiver)	0.2% (1)
Supported Employment	5.1% (21)
Other, please specify:	5.1% (21)

Would you describe this setting as located in a rural area, located in a suburban area, or located in an urban area?

	Percent (n)
Located in a rural area (located outside of a metropolitan area)	37.8% (153)
Located in a suburban area	34.3% (139)
Located in an urban area	27.9% (113)

What entity/entities control(s) the policies or procedures for this setting?

	Percent (n)
The parent agency/organization	84.0% (341)
The individual setting	11.3% (46)
A subsidiary or foundation	0.2% (1)
Other, please specify:	4.4% (18)

Others mentioned: Board of Directors, Both parent and individual setting, Both the individual setting and the parent organization, Both the parent agency and the individual setting, Both the parent organization and the individual setting, Both the setting and the parent agency, IL Dept. of Human Services, Illinois Department of Transportation, The Board of Directors, The parent agency/organization; The individual setting, Volunteer Board of Director form member churches and Executive Director

Please select all of the following that describe this setting:

	Percent (n)
Multiple settings co-located/campus	14.2% (58)
A gated/secured community	1.2% (5)
Stand-alone building located on a public street or highway	84.6% (346)
Hospital	0.5% (2)
Nursing homes	0.7% (3)

Setting Characteristics

The next set of questions deal with the accommodations provided by your non-residential setting for participants. How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Persons without disabilities (other than staff members) engage with the participants at this setting.

	Percent (n)
Strongly agree	43.5% (175)
Somewhat agree	29.1% (117)
Neither agree nor disagree	8.2% (33)
Somewhat disagree	12.9% (52)
Strongly disagree	6.2% (25)

Community members are NOT allowed to visit the setting at any time.

	Percent (n)
Strongly agree	2.0% (8)
Somewhat agree	2.7% (11)
Neither agree nor disagree	4.0% (16)
Somewhat disagree	13.4% (54)
Strongly disagree	77.9% (314)

Participants at the setting use a common entrance.

	Percent (n)
Strongly agree	71.1% (286)
Somewhat agree	14.4% (58)
Neither agree nor disagree	3.7% (15)
Somewhat disagree	3.0% (12)
Strongly disagree	7.7% (31)

The setting is located in the same physical structure where participants live or are treated on a permanent or temporary basis.

	Percent (<i>n</i>)
Strongly agree	4.4% (18)
Somewhat agree	3.5% (14)
Neither agree nor disagree	2.0% (8)
Somewhat disagree	3.5% (14)
Strongly disagree	86.7% (351)

Participants are free to move about public areas within the setting (common areas, dining rooms).

	Percent (<i>n</i>)
Strongly agree	74.6% (302)
Somewhat agree	17.5% (71)
Neither agree nor disagree	2.5% (10)
Somewhat disagree	4.2% (17)
Strongly disagree	1.2% (5)

Participants have the opportunity to access areas that provide privacy while at the setting (excluding restroom facilities).

	Percent (<i>n</i>)
Strongly agree	68.6% (227)
Somewhat agree	17.6% (71)
Neither agree nor disagree	5.2% (21)
Somewhat disagree	6.4% (26)
Strongly disagree	2.2% (9)

Community members come to the setting to discuss external community activities.

	Percent (<i>n</i>)
Strongly agree	31.9% (128)
Somewhat agree	31.9% (128)
Neither agree nor disagree	16.0% (64)
Somewhat disagree	9.0% (36)
Strongly disagree	11.2% (45)

Once an individual has made the choice of your setting, please select the one statement that best describes the level of individual choice at the setting.

	Percent (n)
Participants have complete control over the type of care or assistance they receive or from whom they receive care or assistance from.	20.6% (83)
While participants have a lot of choice in the type of care or assistance they receive or from whom, they are not in complete control.	75.7% (305)
Participants have little choice in the type of care or assistance they receive and not have control over from whom they receive care or assistance.	3.7% (15)

Community Activities

The first set of questions deal with access to community activities (events occurring external to your setting such as religious services, shopping, employment, or other social/personal/family events outside of the setting). We are interested in how participants participate in unscheduled and scheduled community activities at your setting.

How often, if at all, do participants participate in community activities while residing at the setting? Would you say that the majority of participants participate in these activities regularly, occasionally, or not often at all?

	Percent (n)
Regularly	55.3% (223)
Occasionally	35.5% (143)
Not often at all	9.2% (37)

Is helping participants obtain volunteer opportunities part of your service?

	Percent (n)
Yes	67.0% (236)
No	33.0% (116)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants talk about community activities occurring outside of the setting.

	Percent (n)
All of the time	41.0% (163)
Most of the time	29.1% (116)
Some of the time	28.4% (113)
Never	1.5% (6)

Participants have the opportunity to engage in community activities while at the setting (both at the setting and in the community).

	Percent (n)
All of the time	35.8% (142)
Most of the time	29.0% (115)

Some of the time	32.2% (128)
Never	3.0% (12)

Participants and community members interact at the setting.

	Percent (n)
All of the time	25.1% (100)
Most of the time	17.1% (68)
Some of the time	52.0% (207)
Never	5.8% (23)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Participants do NOT know where to find information on community activities.

	Percent (n)
Strongly agree	3.3% (13)
Somewhat agree	9.6% (38)
Neither agree nor disagree	20.9% (83)
Somewhat disagree	26.2% (104)
Strongly disagree	40.1% (159)

There are setting rules that prohibit participants from coming and going as they please.

	Percent (n)
Strongly agree	25.1% (100)
Somewhat agree	31.4% (125)
Neither agree nor disagree	12.6% (50)
Somewhat disagree	11.6% (46)
Strongly disagree	19.3% (77)

Participants are given easy access to the community outside of the setting.

	Percent (n)
Strongly agree	32.6% (130)
Somewhat agree	34.8% (139)
Neither agree nor disagree	17.5% (70)
Somewhat disagree	10.3% (41)
Strongly disagree	4.8% (19)

Is helping participants obtain integrated employment opportunities part of your service?

	Percent (n)
Yes	59.9% (227)
No	40.1% (152)

Only answer these questions if you answered “yes” to the question above. If your setting does not provide employment opportunities, please continue to the next page.

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants pursue integrated /competitive employment opportunities.

	Percent (n)
All of the time	22.9% (57)
Most of the time	14.9% (37)
Some of the time	56.6% (141)
Never	5.6% (14)

Participants pursue other employment opportunities (both paid and volunteer).

	Percent (n)
All of the time	26.5% (66)
Most of the time	20.5% (51)
Some of the time	48.2% (120)
Never	4.8% (12)

Interested participants are given the resources on how to obtain employment.

	Percent (n)
All of the time	66.3% (165)
Most of the time	20.1% (50)
Some of the time	10.8% (27)
Never	2.8% (7)

Personal Accommodations (Dining and Travel)

The next set of questions deal with travel accommodations provided by your non-residential setting. We are interested in the transportation opportunities and access at your setting. How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

There are NO public transportation opportunities available to participants to/from the setting.

	Percent (n)
Strongly agree	8.9% (36)
Somewhat agree	11.6% (47)
Neither agree nor disagree	3.5% (14)
Somewhat disagree	27.7% (112)
Strongly disagree	48.4% (196)

The setting provides transportation opportunities to participants outside of regularly schedule options.

	Percent (n)
Strongly agree	36.2% (146)
Somewhat agree	31.3% (126)
Neither agree nor disagree	5.2% (21)
Somewhat disagree	14.6% (59)

Strongly disagree	12.7% (51)
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Are retail businesses near your setting?

	Percent (n)
Yes	83.2% (332)
No	16.8% (67)

Does your setting provide regularly scheduled transportation opportunities to participants? (This includes transportation to community activities, transportation to community services, transportation to/from setting).

	Percent (n)
Yes	90.3% (363)
No	9.7% (39)

Only answer these questions if you answered “yes” to the questions above. If your setting does not provide transportation opportunities, please continue to the next page.

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Participants are informed/educated on how to use public transportation opportunities.

	Percent (n)
All of the time	57.9% (212)
Most of the time	21.6% (79)
Some of the time	18.0% (66)
Never	2.5% (9)

Participants use the transportation opportunities provided by the setting.

	Percent (n)
All of the time	65.6% (239)
Most of the time	25.2% (92)
Some of the time	9.0% (33)
Never	0.3% (1)

Participants know how to contact a staff member about transportation opportunities.

	Percent (n)
All of the time	64.5% (236)
Most of the time	21.9% (80)
Some of the time	12.0% (44)
Never	1.6% (6)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Transportation opportunities are limited for participants.

	Percent (<i>n</i>)
Strongly agree	15.9% (58)
Somewhat agree	33.2% (121)
Neither agree nor disagree	9.0% (33)
Somewhat disagree	24.4% (89)
Strongly disagree	17.5% (64)

Participants feel confident using the transportation opportunities provided by the setting.

	Percent (<i>n</i>)
Strongly agree	76.5% (280)
Somewhat agree	17.8% (65)
Neither agree nor disagree	3.8% (14)
Somewhat disagree	0.8% (3)
Strongly disagree	1.1% (4)

Does your setting provide a space for participants to have a meal at the setting?

	Percent (<i>n</i>)
Yes	95.0% (384)
No	5.0% (20)

Only answer these questions if you answered “yes” to the questions above. If your setting does not provide dining/food accommodations, please continue to the next page.

Participants are assigned seating during meal-times.

	Percent (<i>n</i>)
Strongly agree	3.4% (13)
Somewhat agree	13.6% (52)
Neither agree nor disagree	5.5% (21)
Somewhat disagree	13.8% (53)
Strongly disagree	63.7% (244)

Participants are able to set their own dining/meal-time schedule.

	Percent (<i>n</i>)
Strongly agree	9.9% (38)
Somewhat agree	15.4% (59)
Neither agree nor disagree	9.6% (37)
Somewhat disagree	32.3% (124)
Strongly disagree	32.8% (126)

Participants do NOT engage with others during meal-times.

	Percent (<i>n</i>)
Strongly agree	1.6% (6)
Somewhat agree	0.3% (1)
Neither agree nor disagree	1.3% (5)
Somewhat disagree	7.9% (30)
Strongly disagree	89.0% (339)

Does your setting provide or arrange for meals and food for participants while at the setting?

	Percent (<i>n</i>)
Yes	35.6% (143)
No	64.4% (259)

When it comes to dining/food options, would you say that a typical individual has a lot of choice, some choice, or no choice at all?

	Percent (<i>n</i>)
A lot of choice	22.4% (32)
Some choice	74.8% (107)
No choice at all	2.8% (4)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

There is more than one meal option during meal-times.

	Percent (<i>n</i>)
All of the time	35.7% (51)
Most of the time	25.2% (36)
Some of the time	27.3% (39)
Never	11.9% (17)

Between designated meal-times, the setting provides other food or refreshments.

	Percent (<i>n</i>)
All of the time	60.8% (87)
Most of the time	14.0% (20)
Some of the time	18.9% (27)
Never	6.3% (9)

Personal Autonomy and Choice in Care Options

The next set of questions deals with individual choice when it comes to their care and services provided. First, we are interested in how often participants are asked about their needs and preferences.

Thinking about the average individual at your setting, were they asked about their goals and aspirations in the past 12 months?

	Percent (<i>n</i>)
Yes	97.1% (368)
No	1.6% (6)
Don't know	1.3% (5)

How often, if at all, do participants make changes to their plan of care?

	Percent (<i>n</i>)
Never	0.6% (2)
Annually	10.0% (36)
Semi-annually	16.7% (60)
Monthly	3.1% (11)
As needed/ requested	69.7% (251)

Please select whether the following occur all of the time, most of the time, some of the time, or never.

Individual complaints are addressed in a timely manner.

	Percent (<i>n</i>)
All of the time	77.9% (299)
Most of the time	22.1% (85)
Some of the time	0% (0)
Never	0% (0)

Participants make changes to their plan of care as needed.

	Percent (<i>n</i>)
All of the time	57.8% (222)
Most of the time	24.7% (95)
Some of the time	14.8% (57)
Never	2.6% (10)

Participants with concerns, discuss the concerns with the setting staff.

	Percent (<i>n</i>)
All of the time	67.5% (258)
Most of the time	28.0% (107)
Some of the time	3.7% (14)
Never	0.8% (3)

Participants provide input into their daily schedules.

	Percent (<i>n</i>)
All of the time	45.8% (175)
Most of the time	35.9% (137)
Some of the time	17.3% (66)
Never	1.0% (4)

Staff members do NOT discuss participants with other staff members in public spaces.

	Percent (<i>n</i>)
All of the time	71.9% (274)
Most of the time	18.9% (72)
Some of the time	2.1% (8)
Never	7.1% (27)

When an individual files a complaint, it is considered confidential.

	Percent (<i>n</i>)
All of the time	92.4% (355)
Most of the time	7.0% (27)
Some of the time	0.3% (1)
Never	0.3% (1)

When needed, participants know how to request a new/additional service.

	Percent (<i>n</i>)
All of the time	39.4% (151)
Most of the time	42.8% (164)
Some of the time	16.4% (63)
Never	1.3% (5)

Participants have the opportunity to express their level of satisfaction with the services they are receiving.

	Percent (<i>n</i>)
All of the time	89.7% (341)
Most of the time	7.9% (30)
Some of the time	2.4% (9)
Never	0% (0)

How much, if at all, do you agree with the following statements about your setting? Do you strongly agree, somewhat agree, neither agree nor disagree, somewhat disagree, or strongly disagree?

Participants do NOT feel comfortable expressing concerns regarding their care.

	Percent (<i>n</i>)
Strongly agree	1.0% (4)
Somewhat agree	1.3% (5)
Neither agree nor disagree	3.9% (15)
Somewhat disagree	16.4% (63)
Strongly disagree	77.9% (297)

Participants do NOT know how make changes to their plans of care.

	Percent (<i>n</i>)
Strongly agree	0.8% (3)
Somewhat agree	10.8% (41)
Neither agree nor disagree	11.3% (43)
Somewhat disagree	32.5% (124)
Strongly disagree	44.6% (170)

Information on how to file a complaint is easily accessible to participants.

	Percent (<i>n</i>)
Strongly agree	68.7% (263)
Somewhat agree	18.3% (70)
Neither agree nor disagree	5.5% (21)
Somewhat disagree	2.1% (8)
Strongly disagree	5.5% (21)

Participants do NOT have a choice of which provider staff delivers care/support.

	Percent (<i>n</i>)
Strongly agree	4.5% (17)
Somewhat agree	22.0% (84)
Neither agree nor disagree	13.6% (52)
Somewhat disagree	25.9% (99)
Strongly disagree	34.0% (130)

Individual requests regarding their care are forwarded to independent/non-setting based case manager.

	Percent (<i>n</i>)
Strongly agree	40.6% (155)
Somewhat agree	24.3% (93)
Neither agree nor disagree	12.8% (49)
Somewhat disagree	8.4% (32)
Strongly disagree	13.9% (53)

Schedules for PT, OT, medication, diet, or other care options are posted in common areas (i.e., hallways).

	Percent (<i>n</i>)
Strongly agree	7.3% (28)
Somewhat agree	6.8% (26)
Neither agree nor disagree	14.4% (55)
Somewhat disagree	8.1% (31)
Strongly disagree	63.3% (241)