

An Evaluation of Person-Centered Planning in Illinois Adult DD Waiver Services

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Report prepared by:

Caitlin Crabb, PhD, MPH &
Tamar Heller, PhD &
Kelly Hsieh, PhD
Institute on Disability and Human Development

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List of Abbreviations

| | |
|------|--|
| AT | Assistive technology |
| BQM | Bureau of Quality Management |
| CDS | Community Day Services |
| CILA | Community Integrated Living Arrangement |
| CST | Community support team |
| DD | Developmental disability |
| DSP | Direct Support Professional |
| HCBS | Home and community-based services |
| HRST | Health Risk Screening Tool |
| ISC | Independent Service Coordinator |
| ISP | Individual's Services Plan |
| PI | Principal Investigator |
| QIDP | Qualified Intellectual Disabilities Professional |

Executive Summary

Background

Person-centered planning using conflict-of-interest-free case management is a requirement for people receiving Medicaid waiver services. In 2017, Illinois transitioned the responsibility of writing the Personal Plan to Independent Service Coordinators which had previously been the responsibility of service providers. Service providers are responsible for writing Implementation Strategies that reflect what is written in the Personal Plan. In the spring of 2021, the Division of Developmental Disabilities within the Illinois Department of Human Services contracted with the Institute on Disability and Human Development at the University of Illinois at Chicago to evaluate the person-centered planning process and make recommendations to improve the process for all stakeholders.

Methods

This evaluation used a variety of data sources conducted at various time points between April and December 2021. Data sources included the following: 1) virtual interviews with a variety of stakeholders, 2) an online Qualtrics survey, 3) virtual feedback at Division meetings, 4) a virtual Implementation Strategies workgroup, 5) focus groups with self-advocates, and 6) review of documents provided by Division staff and various stakeholders related to person-centered planning.

Summary of Recommendations

1. Provide robust, consistent, and ongoing training through the Division on the person-centered planning process and concepts to all stakeholders and also consider the training needs of specific groups of stakeholders.

2. Identify a point person within BQM to act as technical assistance and to provide training on person-centered planning to people with disabilities, families, ISCs, and providers, families.

3. Clearly identify and communicate where information related to the person-centered planning process is housed within the Division. Ensure that information matches across documents and platforms.

4. Ensure better communication and collaboration among ISCs and providers in the person-centered planning process.

5. Ensure accessibility, consistency, and completeness of person-centered planning documents by the ISC.

6. Ensure accessibility, participation, and preferences of the individual within person-centered planning meetings with ISCs.

Introduction

Person-centered planning using conflict-of-interest-free case management is a requirement for people receiving Medicaid waiver services. In 2017, Illinois transitioned the responsibility of writing the Personal Plan, a part of the person-centered planning process, to Independent Service Coordinators (ISCs) which had previously been the responsibility of service providers. Service providers are responsible for writing Implementation Strategies that reflect what is written in the Personal Plan. In the spring of 2021, the Division of Developmental Disabilities (“the Division”) within the Illinois Department of Human Services contracted with the Institute on Disability and Human Development at the University of Illinois Chicago to evaluate the person-centered planning process and make recommendations to improve the process for all stakeholders.

The following questions guided the evaluation process:

1. Where and what are the breakdowns in the person-centered planning process?
2. What is working well in the person-centered planning process and how can those components be maximized?
3. What are the information and training needs around person-centered planning for all stakeholders?
4. What do stakeholders deem important to improve this process?
5. What updates to current person-centered planning documents and tools would better facilitate the process?

The ultimate goal of the evaluation was to provide attainable recommendations to the Division to improve this process. Monitoring of the approved recommendations will follow their implementation.

Background

History of Person-Centered Planning Philosophy and Models

Person-centered planning has evolved since 1979, taking at least eleven distinct forms and spreading globally prior to taking its current form (O'Brien & O'Brien, 2000). Person-centered planning began as a part of the deinstitutionalization movement for the purpose of increasing the individual's involvement in their own treatment decisions and future planning (Callicott, 2003). The concept behind person-centered planning was initially made popular by Karen Green-McGowan and Mary Kovaks as they shared their workshops on 24-hour planning in 1979. Between 1980 and 1992, person-centered planning evolved through several distinct types of client-centered approaches, which are described in **Error! Reference source not found.** in the Appendix. The term "person-centered planning" became the common vernacular used to describe this approach by 1985 and is used today. The focus of person-centered planning places the individual at the center of their supports across five dimensions of experience, including: 1) community presence, 2) choice, 3) respect, 4) competence, and 5) community participation (O'Brien, 1987).

History of Person-Centered Planning in Illinois

Prior to July 1, 2016, ISCs participated in the Individual Service Plan (ISP) process but were not the primary facilitators. They attended the ISP meeting(s), were part of the community support team, and signed off on the ISP. Per Rule 115.230(a), which can be found in Title 59 of the Illinois Administrative Code, effective March 17, 2003, which relates to Community Integrated Living Arrangements (CILAs), community support teams (CSTs) were responsible for "preparing, revising, documenting and implementing a single individual integrated services plan for each individual." Furthermore, CSTs consisted of the Qualified Intellectual Disabilities Professional (QIDP), the individual receiving services,¹ the individual's guardian if applicable, non-CILA service providers, and Direct Support Professionals (DSPs) and the ISC Case

¹ Individuals with a DD receiving Division waiver services, or new to receiving DD waiver services, will be referred to as "individuals receiving services" or simply "individuals" for the remainder of the report for consistency and clarity.

Manager. In addition to the CST, the process could include others providing supports outside of those on the CST, and professionals who “assess the individual's strengths and needs, level of functioning, presenting problems and disabilities, service needs and who assist in the design and evaluation of the individual's services plan.” (Rule 115.230(c)). The plans themselves were typically referred to as “Individual’s Services Plans” or ISPs. The ISP is required to address goals of independence in daily living, economic self-sufficiency, and community integration (Rule 115.230(h)). These plans were to be *reviewed* by the CST at least annually and document progress or a lack of progress to re-assess or modify the plan (Rule 115.230(n)).

We would be remiss if we didn’t acknowledge the work that has already been done in Illinois around person-centered planning, primarily through the Life Choices Initiative. The Life Choices Initiative was a collaboration of the Illinois Council on Developmental Disabilities, the National Association of State Directors of Developmental Disabilities Services, and the Division of Developmental Disabilities (Division of Developmental Disabilities, n.d.). The overall intent was to “improve the design and delivery of the supports and services in the developmental disabilities system” in Illinois with primary foci of streamlining the waiting list for services and “improving service planning, implementation and monitoring”. A total of six teams were developed to inform and make recommendations in their respective areas. These teams were composed of a variety of stakeholders including family members, ISCs, providers, and trade organizations, along with Division staff and the National Association of State Directors of Developmental Disabilities Services. These teams met over the course of several years and were tasked with assignments. One team was responsible for designing the person-centered planning process that is in place currently; Discovery Tools were created out of that process.

The Life Choices Initiative set the groundwork for the person-centered planning process that is currently in use in Illinois today. ISCs are now responsible for completing the Discovery process using the Discovery Tool in addition to writing the Personal Plan. Providers are now responsible for writing Implementation Strategies based on the Personal Plan. These documents and processes must be conducted or updated at least

annually. This current process is explained in greater detail in the **Error! Reference source not found.** section under Person-Centered Planning Process Map.

Federal Requirements

Federal regulations require the following in the person-centered planning process: 1) includes people chosen by the person; 2) provides support and/or information so that the person can direct the process to the maximum extent; 3) is timely and occurs at a time and place that is convenient to the person; 4) reflects cultural considerations and is accessible to the person; 5) includes strategies for solving conflict or disagreements that come up during the process; 6) offers the person a choice of services and supports that they receive; 7) includes a method for the person to request updates to their plan; and 8) records alternative home and community-based services (HCBS) options considered by the person ("Services: Requirements and Limits Applicable to Specific Services," 2014).

The plan itself must consider the important services and supports for an individual as identified through an assessment of functional needs and reflect the individual's preferences for the delivery of these services and supports. Taking into consideration the individual's identified need and what services and supports are available under the HCBS waiver, the written plan must: 1) document that the person chose the HCBS setting that they are living in; 2) identify the individual's strengths and preferences; 3) identify the individual's clinical and support needs; 4) identify the individual's desired goals or outcomes; 5) identify paid and unpaid services and supports that will support the person to achieve their desired outcomes; 6) address risk factors and strategies to mitigate risk; 7) be accessible to the person and their supporters; 8) identify the person who is responsible for monitoring the plan; 9) be agreed to by the person who the plan is written for and those responsible for its implementation; 10) be given to the person and others who were involved in creating the plan; 11) include information about self-directed services; 12) document prevention of unnecessary or inappropriate services and supports; and 13) document that any modification of Settings Rule requirements are supported by the specific assessed need and include justification in the plan ("Services: Requirements and Limits Applicable to Specific Services," 2014). The plan must be reviewed and revised based on

reassessment of functional need at least yearly, when the person's circumstances or needs significantly change, or when the individual requests an update.

Methods

Data Sources

A variety of data collection methods were used in this evaluation at various time points between April and December 2021. Data collection including the following methods: 1) virtual interviews with a variety of stakeholders, 2) an online Qualtrics survey, 3) virtual feedback at Division meetings, 4) a virtual Implementation Strategies workgroup, 5) focus groups with self-advocates, and 6) review of documents provided by Division staff and various stakeholders related to person-centered planning.

Individual Interviews

Individual and small groups interviews included 18 current Division staff, one former Division staff, eight service provider agencies, eight ISC agencies, four Ligas stakeholders, six family members, four advocates/advocacy organizations, and two self-advocates.

Qualtrics Survey

A Qualtrics survey, through the University of Illinois Chicago Qualtrics platform, was distributed initially in July 2021 via a Division listserv to a variety of stakeholders, including service providers, ISCs, family members, self-advocates, and others. A reminder e-mail was sent through the listserv on August 18, 2021. Responses were downloaded on August 28, 2021, with a total of 335 valid responses collected, as totally blank surveys or surveys that did not fill out any of the questions beyond respondent type were deleted. The largest group of survey respondents was service providers which made up 44% of responses, followed by ISCs at 21% of responses, family members at 20%, other at 9%, and self-advocates at 6% of responses. Due to the low response from self-advocates, an additional effort was made to increase self-advocate survey responses by tapping into stakeholders that work directly with self-advocates. It was decided that focus groups with self-advocates would be more fruitful and

accessible than surveys, so four focus groups with self-advocates were conducted. More detail about these focus groups can be found in the next section.

The survey included the following five questions:

1. In your experience, what parts of the person-centered planning process do you think are working well?
2. In your experience, what parts of the person-centered planning process are not working well or seem to be breaking down?
3. What parts of the person-centered process need to be made clearer and more consistent?
4. We understand that training is an area that could be expanded for a variety of DD stakeholders. What training topics do you feel would be helpful for yourself or for other stakeholders to improve the person-centered planning process in Illinois?
5. Would you be willing to talk more with Caitlin about the person-centered planning process as you see it? If yes, please provide your name, professional affiliation (if applicable), and preferred contact information.

Focus Groups with Self-Advocates

Due to the low response rate of self-advocates on the survey, the Principal Investigator (PI) connected with Leanne Mull who regularly works with self-advocates. She suggested conducting focus groups to circumvent the issue of self-advocates not always having access to e-mail. A total of four virtual focus groups were held between October and November 2021 with 16 self-advocate participants in total. Questions from the survey were adapted to be more accessible during the focus groups. The following questions were included in the focus group guide, though not all were asked during every focus group depending on level of understanding of the person-centered planning process:

- Do you get to invite people to your meeting with your ISC?
- Do you get to decide when and where the meeting is?

- When your ISC has a meeting with you, how do you feel about all the questions that they ask you? Are there questions you like? Are there questions you don't like?
- Do you get to decide what your outcomes are?
- What do you like about the person-centered planning process?
- What don't you like about the person-centered planning process?
- Are there things about the person-centered planning process that are confusing to you?
- Do you need education or training about anything on the person-centered planning process? Are there other people that you think need training about this?
- Was it better or worse when your provider worked with you on your Plan?

Feedback at Division Meetings

Feedback was elicited through pre-established Division-related meetings including at the Division-ISC meeting (5/19/2021), the Developmental Disability (DD) Advisory Committee meetings (9/21/2021 and 11/9/2021), and the Division-Assistive Technology Subcommittee meetings (9/23/2021, 10/21/2021, and 11/4/2021).

Implementation Strategies Input Group

During a DD Advisory Committee meeting on 9/21/2021, it was suggested that a workgroup be formed to discuss the standardization of an Implementation Strategies template, or additional guidance on what is required within the Implementation Strategies that providers are responsible for composing once the Personal Plan is finalized and approved. The first Workgroup meeting took place on 10/4/2021 with 22 people in attendance and the second and final Workgroup meeting took place on 11/10/2021 with 25 people in attendance. For those that expressed interest but could not attend the Workgroup meetings, they were encouraged to provide feedback via e-mail. Notes from the meetings were distributed to all that expressed an interest in participating in the Workgroup after the meetings.

Document Review

Documents were collected by the PI through a number of means. Some documents were shared with the PI at the direction of Division staff that felt they would be useful for this evaluation. Other documents were requested by PI during interviews in which interviewees noted documents that may be useful for this evaluation. Documents reviewed included the following:

- Discovery Tools, Personal Plans, and Implementation Strategies from each ISC and from providers who felt they had good Implementation Strategies and from providers they felt had problematic Implementation Strategies (two good and two problematic, for a total of four sets from each ISC)
- Implementation Strategies templates from 16 provider agencies, as requested by the PI and voluntarily shared by provider agencies
- Provider agency documents related to risk, rights, and planning
- State-operated developmental center documents to understand the process they use for annual planning
- Examples of PATHs
- Person-centered planning conceptual documents
- Life Choices documents
- Managed Care Organizations' Best Practices in Person-Centered Planning documents

Data Analysis

Thematic analysis is a method used to organize and analyze patterns within qualitative data (Braun & Clarke, 2006) and was used within this evaluation. Survey results were analyzed by using open coding to create a list of codes. Codes were compiled into a larger list to identify themes, which were defined as codes that occurred more than once. Themes were then sorted.

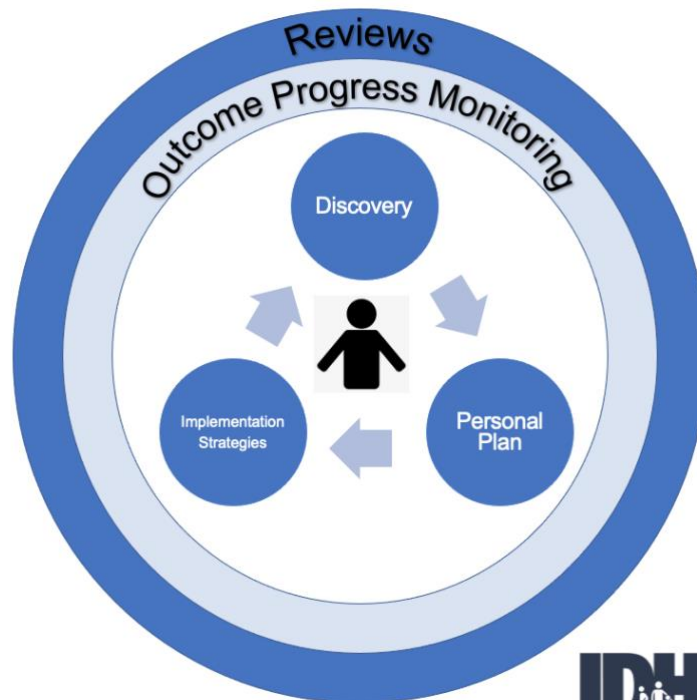
Interviews, meeting notes, and self-advocate focus groups were analyzed in a similar fashion by reviewing for codes and then sorting into themes. Applicable documents were reviewed and notes were taken to identify points of interest.

Person-Centered Planning Process Map

The project began with the development of two Person-Centered Planning Process Maps, the first provides a general overview of the process (Figure 1) and the second contains more detail about the process including the parts that make up the component, when the component is initiated or updated, participants within the component, and the entity responsible for the component (Figure 2). These two maps were developed for stakeholders to use as a visual to more easily identify a part of the process that was working well or not working well. This was included in the person-centered planning survey for respondents to review prior to answering the survey questions.

Figure 1 shows an overview of the person-centered planning process. Pictured are three concentric circles. The innermost circle, in white, contains three smaller, dark blue circles arranged in a triangle and each circle is labeled “Discovery”, “Personal Plan”, and “Implementation Strategies”. The three smaller circles are connected by light blue arrows to indicate an ongoing, cyclical process. These three circles represent the three primary documents that make up the person-centered planning process itself. The Discovery document, sometimes referred to as the “Discovery Tool”, is intended to be used by the ISC to collect information about the person receiving services or about a person who will be receiving services. The Personal Plan is intended to be a summary of the person’s outcomes, risks, barriers to achieving outcomes, and services and supports based on the Discovery Tool. Lastly, the Implementation Strategies are completed by service providers and outline how they will support outcomes laid out in the Personal Plan, address risk identified in the Personal Plan, and provide other pertinent services and supports. Within this triangle of small dark blue circles is a figure of a person to remind viewers that the intent of the person-centered planning process is to have the person at the center of it.

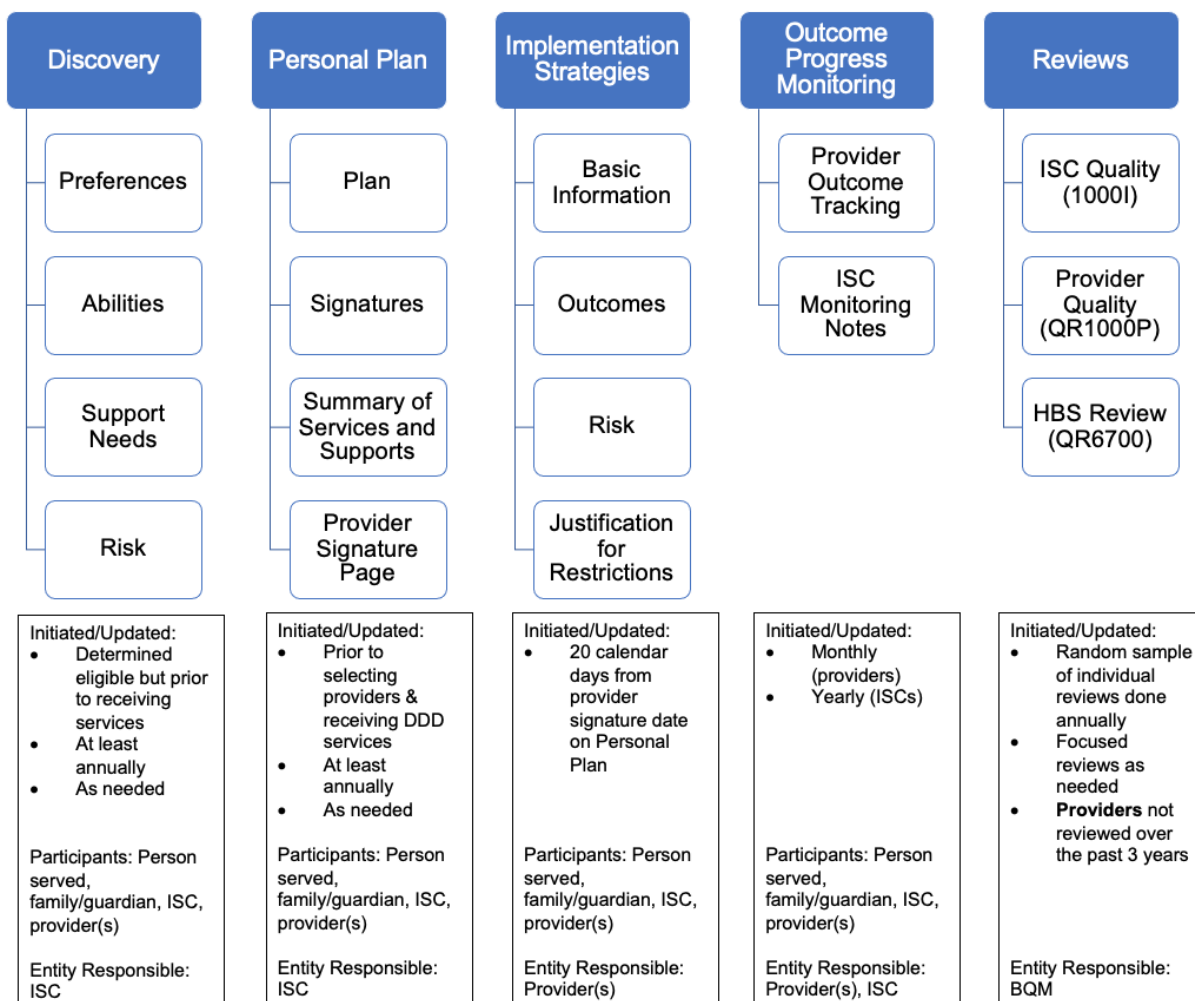
Figure 1. Person-Centered Planning Process Map – Overview



The next concentric circle, shaded in light blue, contains black text that reads “Outcome Progress Monitoring”. This includes monitoring of progress toward outcomes outlined in the Personal Plan by both service providers and ISCs. The outermost concentric circle, shaded in dark blue, contains black text that reads “Reviews”. These reviews are conducted by the Bureau of Quality Management (BQM) within the Division.

Figure 2 shows the person-centered planning process in more detail. It includes required parts for each of the three documents, and forms to be completed during the outcome progress monitoring and review components of the process. Across the top are five boxes, shaded in dark blue that read, from left to right, “Discovery”, “Personal Plan”, “Implementation Strategies”, “Outcome Progress Monitoring”, and “Reviews”.

Figure 2: Person-Centered Planning Process Map – Detailed



The middle section of Figure 2 shows the required parts for each component. Below the “Discovery” box are four vertical white boxes that read, from top to bottom, “Preferences”, “Abilities”, “Support Needs”, and “Risk”. Underneath “Personal Plan” are four vertical white boxes, that read, from top to bottom, “Plan”, “Signatures”, “Summary of Services and Supports”, and “Provider Signature Page”. Four white boxes appear vertically under “Implementation Strategies”, and read, from top to bottom, “Basic Information”, “Outcomes”, “Risk”, and “Justification for Restrictions”. Two boxes lie beneath “Outcome Progress Monitoring”, reading “Provider Outcome Tracking” and beneath that, “ISC Monitoring Notes”. Lastly, under the “Reviews” box, lies three vertically-oriented boxes reading, from top to bottom, “ISC Quality (1000I)”, “Provider Quality (QR1000P)”, and “HBS Review (QR6700)”. These represent the three forms that BQM uses to assess the person-centered planning process at the ISC, provider, and home-based services levels.

At the bottom of Figure 2 are five boxes which align with each of the five components of the person-centered planning process. These boxes contain information about when the particular component needs to be completed or updated, who participates in that particular component, and who is responsible for carrying out that particular component. The Discovery process must be completed once someone has been determined eligible for DD waiver services but prior to the development of the Plan and the search for potential providers. For individuals who are already receiving DD waiver services, the Discovery process must be updated at least annually or as needed if there is a significant change *or* if the individual requests an update. Discovery participants include the person served, family/guardian, the ISC, and provider(s). The individual can invite whoever they wish to the Discovery meeting(s) and it should be held at a time and place that is convenient for them. The ISC is responsible for completing the Discovery Tool during the meeting(s) with the participating individuals.

For individuals new to waiver services, the Personal Plan must be completed prior to selecting a provider or providers and prior to receiving Division services. For those already receiving Division waiver services, the Personal Plan must be updated at least annually or as needed due to a significant change *or* at the request of the individual. While the ISC writes the Personal Plan based on the Discovery Tool and

meeting, the person with disabilities, their family, and providers are to be included in the process.

Implementation Strategies are completed by the service provider(s) who have agreed to provide services and must be completed within 20 calendar days of their signature(s) on the Personal Plan Provider Signature Page.² The ISC, the person with disabilities, and families are to be included in the writing of the Implementation Strategies.

Outcome Progress Monitoring is completed by both service providers and ISCs. ISCs are required to check-in with the individual and their families at least yearly and check for progress towards outcomes written in the Personal Plan. Providers are to track progress toward outcomes within the Personal Plan on a monthly basis.

BQM conducts reviews of the person-centered planning process through three forms: ISC Quality (1000I), Provider Quality (QR1000P), and HBS Review (QR6700). BQM reviews are not done annually on an individual unlike the other components of the process which are completed at least annually for each individual. Each year, BQM draws a random sample of individuals to review. Providers that have not had an individual reviewed within the past three years are also reviewed. Additionally, BQM may conduct focused reviews as needed.

² Only the following provider types are required to compile Implementation Strategies: Adult Day Care; Agency-based Personal Support Worker, for Home-Based Support program participants only; Child Group Home; CILA; CDS; Community Living Facility; and Supported Employment Program.

Stakeholder Feedback

In total, 2,172 codes from interviews, self-advocate focus groups, and survey responses were collected and assigned themes and sub-themes. The five themes within this evaluation are 1) *Person-Centered Planning Process and Documents* (n = 928 codes, 42.7%), 2) *Person-Centeredness* (n = 385 codes, 17.7%), 3) *Information Dissemination* (n = 327 codes, 15.1%), 4) *Relationships* (n = 268 codes, 12.3%), and 5) *Other* (n = 264 codes, 12.2%). Sub-themes and codes within the Other theme are not discussed below, but are included in Table 2 of the Appendix.

Person-Centered Planning Process and Documents

The theme, *Person-Centered Planning Process and Documents*, includes any breakdown, positive aspect, or recommendation related to the current person-centered planning process in Illinois, including the structure and specific documents or document components. This theme was the most discussed theme within the evaluation: stakeholders talked about this theme 928 times (42.7% of codes) including breakdowns, things working well, and recommendations for the person-centered planning process and documents. In terms of breakdowns and things working well, the top sub-themes were 1) that the Discovery Tool and process were working well, 2) document redundancies, 3) breakdowns in outcomes, 4) breakdowns in timelines, and 5) that the Personal Plan was working well. Other sub-themes and example codes within this theme can be found in Table 2 in the Appendix.

Many interviewees and survey respondents noted that the Discovery Tool and its process was a piece that was generally working well (n = 95 codes, 10.2%). Most of the feedback was from survey respondents who did not elaborate on what about the Discovery Tool or process was working well (n = 54, 56.8%). Stakeholders felt that the Discovery process gave the ISC (and others) an opportunity to learn about the individual and what their wants and needs (n = 24, 25.3%). Some stakeholders like the questions within the Discovery Tool, or indicated that they made sense to them (n = 7, 7.4%).

Some stakeholders felt that process documents were often redundant (n = 56 codes, 6.0%). The majority of codes within this sub-theme indicated that the Discovery

Tool and Personal Plan documents were redundant (n = 45, 80.4%) though other stakeholders felt that the Personal Plan and Implementation Strategies were redundant (n = 8, 14.3%).

Stakeholders felt that there were breakdowns in outcomes (n = 54 codes, 5.8%) primarily because they were unrealistic or unattainable for consumers (n = 6, 11.1%), generic (n = 5, 9.3%), or didn't focus on skill-building (n = 4, 7.4%).

Process timelines were reported to be a breakdown by stakeholders (n = 49 codes, 5.3%). The largest portion of codes were from survey respondents who did not elaborate on what exactly was breaking down in terms of timelines (n = 15, 30.6%). Some stakeholders noted that ISC timelines were a source of process breakdown but did not elaborate on if this was related to getting documents to providers in a timely manner or if this was related to the annual timelines (n = 10, 20.4%). However, other stakeholders noted that ISC to provider timelines *were* the source of breakdowns (n = 8, 16.3%).

Most of the stakeholders that felt that the Personal Plan was working well (n = 35 codes, 3.8%) were survey respondents and did not provide elaboration about what within the Personal Plan was working well (n = 24, 68.6%).

General recommendations from stakeholders related to *Person-Centered Planning Documents and the Current Process* include (n = 388 codes, 41.8%):

- Training or clarification needed on other aspects of the documents and process not listed below (n = 67, 17.3%)
- Training on Implementation Strategies (n = 54, 13.9%) including the expectations for content and the purpose of the document
- Training on Personal Plans (n = 53, 13.7%) including expectations for content, example Plans/writing with different scenarios
- Training on outcome development and identification (n = 42, 10.8%)
- Training and/or clarity needed on timelines (n = 36, 9.3%)
- Training on Discovery Tool and process (n = 29, 7.5%)
- Training on Reviews (n = 23, 5.9%)
- Training on Monitoring (n = 21, 5.4%)
- Add content to Personal Plan (n = 16, 4.1%)

- Combine Discovery and Personal Plan (n = 13, 3.4%)
- Add content or questions to Discovery Tool (n = 13, 3.4%)
- Require an Implementation Strategies template (n = 13, 3.4%)
- Training on risk/barriers/mitigation (n = 8, 2.1%)

Person-Centeredness

The theme, *Person-Centeredness*, includes any breakdown, positive aspect, or recommendation related to person-centeredness within the person-centered planning process and services and supports in Illinois. Stakeholders had feedback related to this theme 385 times (17.7% of codes) for breakdowns, things working well, and recommendations to improve person-centeredness for all stakeholders in the person-centered planning process and in service provision. In terms of breakdowns and things working well, the top sub-themes were 1) a general lack of person-centeredness, 2) the process was person-centered and person-driven, 3) ISCs don't know the individuals they're working with, and 4) a lack of provider buy-in to the process or follow-through. Other sub-themes and example codes within this theme can be found in Table 2 in the Appendix.

There was a feeling of a general lack of person-centeredness in the evaluation (n = 82 codes, 21.3%) though an almost equal number of stakeholders felt that the process was person-centered (see next paragraph for more detail). In particular, stakeholders felt that outcomes were not person-centered (n = 16, 19.5%). Others felt that the process was very much provider-led, or centered around providers (n = 10, 12.2%) and the individual was often not included in the process (n = 9, 11.0%).

Not all stakeholders felt that the process was lacking person-centeredness; in fact, there were 76 codes to the contrary, feeling that the process was person-centered (19.7%). Stakeholders mostly commented on the process being driven by the person (n = 27, 35.5%), but some specifically felt that individuals' preferences were particularly well-integrated in this process (n = 22, 28.9%). Other stakeholders noted that the input that individuals had in their outcomes was working well (n = 12, 15.8%).

Stakeholders frequently talked about the ISC not knowing the individual well enough to facilitate a true person-centered planning process (n = 72 codes, 18.7%).

Most feedback was a general lack of knowledge (n = 30, 41.7%), but stakeholders also expressed that annual meetings to complete the Discovery and/or Personal Plan were not happening at all or did not happen consistently across years (n = 11, 15.3%). Furthermore, stakeholders felt that ISCs did not have enough time with each person to get to know them (n = 11, 15.3%) and that caseloads were too large (n = 10, 13.9%).

There was a sense from some stakeholders that some providers had not bought into the notion of person-centered planning and the current process or were not following through with their parts (n = 41 codes, 10.6%). Several stakeholders did not specify what exactly providers didn't follow through with (n = 15, 36.6%) while others explained that providers do not follow through with outcomes (n = 9, 22.0%).

General recommendations from stakeholders related to *Person-Centeredness* include (n = 59 codes, 15.3%):

- Clarity and/or training needed on how individuals can access supports (n = 23, 39.0%)
- Ensure accessibility of meeting and documents (n = 15, 25.4%)
- ISC training on interviewing and facilitation skills (n = 13, 22.0%)
- Training for people with significant ID or who are non-verbal (n = 8, 13.6%)

Information Dissemination

The theme, *Information Dissemination*, includes any breakdown, positive aspect, or recommendation related to the information dissemination about the person-centered planning process in Illinois, including training on the process. Stakeholders had feedback related to this theme 327 times (n = 15.1% of codes) for breakdowns and recommendations to improve information dissemination for all stakeholders in the person-centered planning process including 1) lack of stakeholder understanding of person-centered planning, 2) breakdown in training, 3) a lack of clear expectations about stakeholder roles and general process expectations, and 4) inconsistent or inaccurate information dissemination. Sub-themes and example codes within this theme can be found in Table 2 in the Appendix.

The most common sub-theme that arose under *Information Dissemination* was that process stakeholders do not fully understand what person-centered planning is (n =

33 codes, 10.1%). Stakeholders felt particularly that providers (n = 8, 24.2%), consumers (n = 8, 24.2%), and families or guardians (n = 7, 21.2%) did not understand the process. Some stakeholders (n = 6, 18.2%) said that consumers and families did not even know who their ISC was, an integral part of the person-centered planning process.

Stakeholders felt that there was a breakdown in training about the current person-centered planning process (n = 29 codes, 8.9%). Several stakeholders expressed that the initial training had breakdowns, or that the content didn't match subsequent trainings on person-centered planning (n = 8, 27.6%). Other stakeholders felt that ISCs lacked adequate training on the process and its components (n = 7, 24.1%).

Stakeholders felt that there was a lack of clear expectations about stakeholder roles and responsibilities in the person-centered planning process (n = 18 codes, 5.5%). The greatest portion of feedback was a general lack of clear expectations (n = 9, 50.0%), though other feedback specifically noted issues with the Discovery process expectations (n = 3, 16.7%) or with the provider's role in the process (n = 3, 16.7%).

Stakeholders spoke about inconsistent and inaccurate information dissemination (n = 15 codes, 4.6%). The majority of the feedback was related to inconsistent or inaccurate information dispensed by BQM that confused stakeholders (n = 12, 80.0%), or was not consistent with documents such as the ISC Manual.

General recommendations from stakeholders related to *Information Dissemination* include (n = 232 codes, 70.9%):

- Training of stakeholders on general process (n = 109, 47.0%)
- Training and/or clarity needed on specific content areas (n = 78, 33.6%)
- Training on stakeholder roles and responsibilities (n = 45, 19.4%)

Relationships

The theme, *Relationships*, includes any breakdown, positive aspect, or recommendation related to relationships among stakeholders involved in the person-centered planning process. Stakeholders had feedback related to this theme 268 times (12.3% of all codes) for breakdowns, things working well, and recommendations to improve stakeholder relationships to improve the person-centered planning process and

service provision in Illinois. In terms of breakdowns and things working well, the top sub-themes were 1) breakdowns in stakeholder communication and collaboration, 2) stakeholder communication and collaboration was working well, 3) a lack of stakeholder accountability and oversight, and 4) positive relationships with ISCs. Sub-themes and example codes within this theme can be found in Table 2 in the Appendix.

Stakeholders spoke about challenging relationships among entities that led to breakdowns in the person-centered planning process (n = 124 codes, 46.3%). Half of the codes in this sub-theme were related to breakdowns in the relationship between providers and ISCs (n = 62, 50.0%). Generally, stakeholders talked about the lack of teamwork within the process (n = 35, 28.2%).

A smaller, but still substantial, portion of codes related positive communication and collaboration efforts among stakeholders (n = 30 codes, 11.2%). Most of this was general feedback about communication and collaboration working well among stakeholders (n = 22, 73.3%) though a few stakeholders mentioned that providers and families/individuals with disabilities had positive relationships (n = 5, 16.7%)

There was a perception that there was a general lack of oversight and accountability of stakeholders (n = 20 codes, 7.5%), almost entirely of providers (n = 17, 85.0%).

Some stakeholders felt that they had a positive relationship with the ISC, or that they viewed relationships of other stakeholders with the ISC as positive (n = 18 codes, 6.7%). Some felt that the current process, with ISCs as conflict-free case management entities, is much stronger than the previous process where providers were responsible for the writing the plans (n = 10, 55.6%). Others saw a positive relationship between the ISC and the individual they were supporting in the person-centered planning process (n = 7, 38.9%)

General recommendations from stakeholders related to *Relationships* include (n = 76 codes, 28.4%):

- Clarify expectations on sharing information, communication, and collaboration (n = 63, 82.9%)
- Clarity needed on oversight and accountability of stakeholders (n = 13, 17.1%)

Recommendations

1. Provide robust, consistent, and ongoing training through the Division on the person-centered planning process and concepts to all stakeholders and also consider the training needs of specific groups of stakeholders.

- Increase the number of trainings and staff time dedicated support to person-centered planning within BQM.
- Ensure consistent and ongoing BQM training about the person-centered planning process, the intent of the documents, roles of stakeholders, and concepts.
- Clearly identify the role and intent of each document in the person-centered planning process for all stakeholders.
 - Smull et al. (2010) provides a list of questions that each stakeholder should be able to answer in terms of expectations, performance, and improvement.
- Develop materials for ISCs to provide to individuals receiving services and their families in plain language in the following areas:
 - Guardianship options and decision-making resources
 - The requirements of the HCBS Settings Rule
 - Information about the Sex Education for Adults with ID/DD Act
- ISC-specific training recommendations:
 - Consider encouraging additional training for ISCs on more intensive methods to facilitate person-centered planning (possibilities include PATH, MAPS, and Charting the LifeCourse; please see Table 1 in the Appendix for more methods).
 - Include scenarios and examples of completed Discovery and Personal Plan documents within trainings. Scenarios could include individuals needing their annual update, an individual who is non-verbal, someone with accessibility support needs, and someone who is a strong self-advocate.
 - Provide examples of Personal Plans that BQM considers exemplary.
 - Incorporate self-advocates within these trainings as leaders.
 - Encourage a mentorship system within ISCs to pair new and experienced ISCs to complete the person-centered planning process. Many ISCs already have this setup.

- Consider investing in a small sample of ISCs and providers (QIDPs) to receive person-centered facilitation certification (e.g., through Relias Academy, Helen Sanderson Associates). While this may not be scalable for all providers and ISCs, the lessons learned could be valuable for the remainder of the system (Smull et al., 2010).
- Self-advocate training recommendations:
 - Empower self-advocates to lead their own meetings to the extent they want and are able to.
 - Ensure accessibility of trainings for self-advocates including using plain language, interpreters, captioning, and pictures as needed.

2. Identify a point person within BQM to act as technical assistance and to provide training on person-centered planning to people with disabilities, families, ISCs, and providers, families.

- Ensure that the BQM individual identified provides a mechanism for families and people with disabilities to receive technical assistance and training about person-centered planning, in addition to providers and ISCs.

3. Clearly identify and communicate where information related to the person-centered planning process is housed within the Division. Ensure that information matches across documents and platforms.

- Maintain a central location, preferably on the Division's website, for families and self-advocates to access information.
 - Stakeholders felt that there wasn't a lack of information in the state, rather than a lack of appropriate distribution. Families don't know where to turn for information, especially families that are new to the system. The Division's website seems to be the most appropriate place for this information.
- Ensure that information matches across documents including the ISC Manual, person-centered planning documents, administrative rules, and the DD Waiver Manual.

4. Ensure better communication and collaboration among ISCs and providers in the person-centered planning process.

- Encourage ISCs to collect input from DSPs familiar with the individual prior to the meeting about things the individual has expressed an interest in working on and other pertinent information.
- Consider a more robust communication requirement or encouragement between providers and ISCs in the process throughout the year, including around the time of Discovery and the Personal Plan.

5. Ensure accessibility, consistency, and completeness of person-centered planning documents by the ISC.

- Require that ISCs document the choices that an individual was given and that they made a choice based on that information within the Discovery Tool and Personal Plan.
- Clearly identify when the annual Discovery process is to begin again; one ISC recommended not to measure from 365 days from the previous Personal Plan signature as it inhibits the ISC's ability to communicate with all requested parties or to retrieve needed documents.
- Encourage ISCs discuss components of the Discovery Tool components throughout the year, during each of the four visits with the individual (effective July 1, 2022).
- Require the documentation of both near-term (outcomes) and long-term goals within the Discovery Tool and Personal Plan as needed.
- Within each section of the Personal Plan without an outcome, require documentation of the reason(s) for not having an outcome in the area.
- On the Personal Plan, further break down the "Revision" category under "Type of Plan" categories on page 1, with the "Revision" category reflecting when abilities or support needs change and an "Edit" category reflecting when preferences or desires change. Add a category of "Update" when information is updated that does not significantly change the content of the Personal Plan.

- Provide clear direction on how transportation and rights restrictions should be documented, and the extent of documentation, within the Personal Plan.
- Provide robust, clear *written* instructions for completion and intent of each document either within the document itself, or as an accompanying document.
- Consider instituting a standardized risk assessment, or offer a choice of approved tools, for all ISCs to use in the development of the Personal Plan.
- Add questions and instructions to the Discovery Tool: see attached document with recommended changes.
- Clearly identify which questions *must* be asked within the Discovery Tool, perhaps by bolding or italicizing them.
- Provide clear direction about which barriers need to be documented and addressed within the Personal Plan: only those related to achieving the outcome or all barriers within the particular domain?
- Standardize the Implementation Strategies for providers. Template attached.
 - The lack of a template and clear guidance for the Implementation Strategies brings into question the quality of some providers' Implementation Strategies.
- Avoid the use of clinical language and/or jargon or ensure that a plain language explanation is included if clinical language and/or jargon are to be used.
- Instruct ISCs to provide alternative versions of the Personal Plan, as needed, for individuals who are blind (audio Personal Plan) or using pictures.
- Consider providing ISCs and providers with examples of person-centered language, such as the table in the state-operated developmental centers' ISP Protocol document.
- Consider limiting the length of the DSP section of the Implementation Strategies
 - Many of these that were reviewed were extremely lengthy. Some stakeholders provided input that the length of these documents discourages people from reading them, especially DSPs, and then they miss key information.
- Assess the need for AT during the Discovery process.

6. Ensure accessibility, participation, and preferences of the individual within person-centered planning meetings with ISCs.

- Ensure that ISCs are Incorporating the person's preferences into the meeting logistics including where, when, and who to invite.
- Encourage participation of DSPs and advocates, which may be DSPs, in meetings as much as possible, when the individual indicates that they would like them to attend.
- Make the meeting(s) as accessible as possible, by including graphics, interpretation, large print material, and providing material in advance.
- Make meetings positive and celebratory, focusing on wins and strengths.

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Appendix

Table 1. Person-Centered Planning Approaches

| Stage of Person-Centered Planning key figure(s) in development | Brief Description of Unique Attributes and Origin |
|--|--|
| Getting to Know You Brost & Johnson | Following the introduction of the initial person-centered planning workshops, “Getting to Know You” was one of several alternative formal person-centered planning methodologies. It was developed in the 1980s for the purpose of gathering information on the needs of the individual in order to develop a general service plan and case management system, while also evaluating an individuals’ support systems and the capacities of such service systems. This methodology is not commonly used today (Brost & Johnson, 1982, pp. 21-22; O'Brien & O'Brien, 2000). |
| Individual Service Design Yates | Rooted in Program Analysis of Service Systems (PASS), this early approach to person-centered planning focused primarily on the experience of the individual. In this methodology, one would seek information about the individual’s experience and personal history for the purpose of understanding the individuals’ identity, and comparing and contrasting the individual’s experience with other members of society (O'Brien & O'Brien, 2000, p. 22; Yates, 1980). |
| Personal Futures Planning Mount & Zwernick | During the period of deinstitutionalization, this early approach to person-centered planning focuses on the primary domains of a person’s overall life (i.e., their history, preferences, dreams/hopes, and relationships). With this method, a group of individuals set timeframes for committed action items that support the individual in moving toward what is considered a favorable direction for them. Much importance is placed on profiling within this type of person-centered planning (Mount, 1992; Mount, 1994; Mount & Zwernick, 1988; O'Brien & O'Brien, 2000, p. 22). |
| 24-Hour Planning Green-McGowan & Kovaks | As one of the earliest phases in the evolution of person-centered planning, the 24-hour planning program originally took the form of workshops led by Karen Green-McGowan and Mary Kovaks. This type of planning focuses on the development of service and support plans that will help the individual function in a way that allows for them to engage in activities that they and their loved one’s view as meaningful. |

| Stage of Person-Centered Planning key figure(s) in development | Brief Description of Unique Attributes and Origin |
|--|---|
| | <p>Complete and technical plans were laid out to achieve this, detailing a plan for each day and week as well as breakdowns of each day. The goal of 24-hour planning is to develop a plan for the individual that more strongly considers the voices of those who are more intimately familiar with the individual, as opposed to weighing more heavily on provider plans (Rooney et al., 2016).</p> |
| New Hats Curtis & Dezelsky | <p>This approach was developed out of concern that service providers were not prioritizing the desires of the individual, thus “extinguish[ing]” the individuals’ dreams. This type of person-centered planning encouraged people to share their dreams, and ultimately led to the development of unique approaches taken by practitioners to support the individual in reaching their desired outcomes (O'Brien & O'Brien, 2000, p. 22).</p> |
| Families First Holden | <p>The Families First approach was an evolution of Personal Futures Planning. This approach prioritized the family involvement in the individualized planning process. Moreover, this approach led to the organization of family members to advocate for system changes focused on education and human services at the local and state level (Holden, 1990; O'Brien & O'Brien, 2000).</p> |
| Whole Life Planning Butterworth | <p>Whole Life Planning was developed as “a way to match planning procedures to the individual preferences of people with developmental disabilities who were seeking employment” (Butterworth et al., 1993; O'Brien & O'Brien, 2000, p. 25).</p> |
| Essential Lifestyle Planning Smull & Burke Harrison | <p>This detailed planning approach to person-centered planning evolved from Personal Futures Planning. Essential Lifestyle Planning aims to establish support the individual to immediately get their preferred and unique lifestyle. Over the years, many tools have been developed to discover the individual’s uniqueness, dreams, and lifestyle preferences (O'Brien & O'Brien, 2000, pp. 25-26; Smull & Burke Harrison, 1992).</p> |
| Group Action Planning Turnbull & Turnbull | <p>Group Action Planning evolved out of MAPS and Personal Futures Planning. The goal is “to empower families to plan, especially families like their own who are concerned to realize great expectations for family members with behavioral challenges.” This is done by</p> |

| Stage of Person-Centered Planning key figure(s) in development | Brief Description of Unique Attributes and Origin |
|--|---|
| | generating a team of people in “creative brainstorming” to support the individual with living their desired life. The five components that make up the Group Action Plan are: “inviting support, creating connections, envisioning great expectations, solving problems, celebrating success” (O'Brien & O'Brien, 2000, p. 25; Turnbull & Turnbull, 1999; Turnbull & Turnbull III, 1996). |
| Personal Histories Landis & Pealer | This form of person-centered planning encourages those involved in the planning process to creatively support the individual to “construct and communicate an account of their life story” (Landis & Pealer, 1990; O'Brien & O'Brien, 2000, p. 25). |
| The McGill Action Planning System (MAPS) Vandercook, York, & Forest | This methodology evolved out of the 24-Hour Planning approach, with an initial focus on children with profound disabilities. Like other forms of person-centered planning, MAPS focuses on the individual's history, dreams, ideas, strengths, etc. and uses this information to develop an action plan to support the individual. In the past, this approach has been highly structured with specific steps outlined, but is evolving into a more flexible approach (O'Brien & O'Brien, 2000, p. 22; Vandercook et al., 1989). |
| Outcome-Based Planning Steere, Wood, Pancsofar, & Butterworth | This form of person-centered planning, adapted from career planning, supports individuals during the transition from school to community employment with a focus on their quality of life (e.g., wages, friendships, self-esteem, and self-direction). The philosophy here being that employment alone may not be sufficient to maintain high quality of life. Rather than focusing on employment itself as the end goal, Outcome-Based Planning concentrates on supporting the individual with the process of overall outcome identification and how they can select a job that helps them to achieve those goals (Steere et al., 1990). |
| Planning Alternative Tomorrows with Hope (PATH) Pearpoint, O'Brien, & Forest | PATH evolved out of MAPS for the purpose of supporting individuals and groups achieve desired outcomes involving sustained and coordinated care. Like other forms of person-centered planning, this approach focuses on the individual's strengths and where they are at present to develop an action plan for |

| Stage of Person-Centered Planning key figure(s) in development | Brief Description of Unique Attributes and Origin |
|--|---|
| | achieving their desired outcome(s) (O'Brien & O'Brien, 2000; Pearpoint et al., 1992). |
| Charting the LifeCourse University of Missouri Kansas City, Missouri University Center for Excellence in Developmental Disabilities (UCEDD) | The Charting the LifeCourse approach was established for individuals with intellectual disabilities. This approach consists of a framework that supports the individual, their family, and service providers with a set of decision-making guidelines. Moreover, this approach provides support to policymakers in facilitating practice and systems change (Gotto et al., 2019). |
| Future is Now Heller & Caldwell | The Future is Now approach was established to provide support with person-centered future planning to adults with intellectual and developmental disabilities and their aging family caregivers using a peer training approach (Heller & Caldwell, 2006). |

Table 2: Themes, Sub-Themes, and Example Codes

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|--|---|---|
| Person-Centered Planning Documents and Process (n = 928, 42.7%) | Discovery Tool and process working well (n = 95, 17.6%) | <ul style="list-style-type: none"> • getting to know the consumer working well • parents/guardians have learned so much about their child through Discovery meetings • Discovery meetings do a good job of fleshing out hopes and dreams |
| | Document redundancies (n = 56, 10.4%) | <ul style="list-style-type: none"> • Discovery Tool and Personal Plan are redundant • Implementation Strategies are a duplicate of what is in the Personal Plan |
| | Breakdowns in outcomes (n = 54, 10.0%) | <ul style="list-style-type: none"> • providers will avoid liable outcomes |
| | Breakdowns in timelines (n = 49, 9.1%) | <ul style="list-style-type: none"> • hard to line up with providers on dates • Plans late from ISCs and hard to keep track of |
| | Personal Plan working well (n = 35, 6.5%) | <ul style="list-style-type: none"> • Personal Plan working well • when it's a good Personal Plan, it's easier to ensure person-centered planning • Personal Plans are thorough |
| | Breakdowns in Discovery Tool and/or process (n = 32, 5.9%) | <ul style="list-style-type: none"> • Discovery questions don't make sense to individual • Discovery feels like an intrusion for some people • Discovery equated with risk assessment but it's not an adequate risk assessment |
| | Breakdowns in Personal Plan (n = 32, 5.9%) | <ul style="list-style-type: none"> • breakdown in Personal Plan • Personal Plan is too wordy and not easily digestible |

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|----------------------|--|--|
| | | <ul style="list-style-type: none"> Personal Plans have little useful content |
| | Breakdowns in Outcome Progress Monitoring (n = 27, 5.0%) | <ul style="list-style-type: none"> breakdown in Outcome Progress Monitoring Outcome Progress Monitoring not happening |
| | Other documents and process breakdowns (n = 22, 4.1%) | <ul style="list-style-type: none"> inconsistent completion of the process among ISCs lengthy/time-consuming process |
| | Breakdowns in Reviews (n = 20, 3.7%) | <ul style="list-style-type: none"> breakdown in Reviews reviewers often look for an ISP structure Reviews need to be more consistent |
| | Implementation Strategies working well (n = 19, 3.5%) | <ul style="list-style-type: none"> Implementation Strategies working well |
| | Breakdowns in Implementation Strategies (n = 19, 3.5%) | <ul style="list-style-type: none"> no Implementation Strategy guidelines no consistent Implementation Strategies template |
| | Documents contain inaccurate or outdated information (n = 19, 3.5%) | <ul style="list-style-type: none"> Personal Plans are often copied and pasted from year to year Personal Plan and Discovery Tool have incorrect information |
| | Other document and process components working well (n = 15, 2.8%) | <ul style="list-style-type: none"> risks and barriers working well life areas working well timeframes working well |
| | Documents missing important content (n = 14, 2.6%) | <ul style="list-style-type: none"> Personal Plans missing important information individual health and safety needs not documented in Personal Plan Career & Income sections are usually terrible no mention of hopes or dreams |
| | Outcomes working well (n = 14, 2.6%) | <ul style="list-style-type: none"> more diversification in outcomes outcomes are not generic |

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|---|--|--|
| | | <ul style="list-style-type: none"> outcomes based on individual (as opposed to provider) focus on outcomes (as opposed to state goals) working well |
| | Outcome Progress Monitoring working well (n = 9, 1.7%) | <ul style="list-style-type: none"> Outcome Progress Monitoring working well |
| | Risk and barriers breakdowns (n = 9, 1.7%) | <ul style="list-style-type: none"> difficult to assess all possible risks focus on risk takes away from outcomes risks are so numerous that it crowds out the Personal Plan |
| Person-Centeredness (n = 385, 17.7%) | Lack of person-centeredness (n = 82, 25.2%) | <ul style="list-style-type: none"> people don't get to pick when and where their meetings are process is based on compliance, not person-centeredness person-centered planning is a medical model process |
| | Person-centered and driven (n = 76, 23.3%) | <ul style="list-style-type: none"> detailed information on wants and desires working well consumer-driven working well benefits seen from people working on outcomes, switching providers, being happier |
| | ISC doesn't know individual (n = 72, 22.1%) | <ul style="list-style-type: none"> ISCs don't know the individual hard to build rapport seeing someone twice a year ISC caseloads too big to get to know consumer high ISC turnover rate (causes issues with continuity of care) |

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|---|--|--|
| | | <ul style="list-style-type: none"> • annuals inconsistent in terms of happening or not |
| | Lack of provider buy-in or follow-through (n = 41, 12.6%) | <ul style="list-style-type: none"> • agencies not on board with the new process • providers don't accept the Personal Plan as "the plan" • providers don't work on outcomes |
| | Lack of provider options and availability (n = 31, 9.5%) | <ul style="list-style-type: none"> • fewer services in rural areas • providers can only provide what's available • can be hard to find supports to support outcomes • clarity needed on implementation, never enough staff to put all these great ideas in place |
| | Breakdowns in planning for people with more significant support needs (n = 13, 4.0%) | <ul style="list-style-type: none"> • ISCs don't have tools to do person-centered-planning with someone with a profound disability • difficult with those with low communication skills |
| | Guardian/family dominance (n = 11, 3.4%) | <ul style="list-style-type: none"> • guardian has more power to dictate meetings since they're smaller • guardians and consumers not always on the same page with outcomes • ISCs siding with guardians over individual • parents dominate conversations |
| Information Dissemination (n = 327, 15.1%) | Lack of stakeholder understanding of person-centered planning (n = 33, 34.7%) | <ul style="list-style-type: none"> • unsure of who ISC is • providers don't have an understanding of person-centered planning • consumers, families, providers don't understand process |

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|-----------------------------------|--|--|
| | Breakdowns in training (n = 29, 30.5%) | <ul style="list-style-type: none"> • initial trainings had inconsistencies • initial training on new [waiver recipients] only • training about best practices theory than on examples • nothing after the initial person-centered planning training |
| | Lack of clear expectations about stakeholder roles and general process expectations (n = 18, 18.9%) | <ul style="list-style-type: none"> • always post-training because of deficits rather than pre-training • no clear plan for process requirements • breakdown in what is expected from providers • lack of clarity on individual's role and responsibilities • confused about intent of Personal Plan and Discovery – where should majority of info be? |
| | Inconsistent or inaccurate information dissemination (n = 15, 15.8%) | <ul style="list-style-type: none"> • different manuals have different language/info • BQM reviewers have differing opinions about how things should be done • BQM said Discovery and Personal Plan have to be identical • BQM reviews contradict ISC training |
| Relationships (n = 268, 12.3%) | Breakdowns in collaboration and communication (n = 124, 64.6%) | <ul style="list-style-type: none"> • no team involvement • lack of communication between providers and ISCs • providers locked out of person-centered planning process • sometimes without input of individual/parent/guardian • getting signatures back is difficult |

| Theme (n = 2,172) | Sub-Theme (n = sum of codes in breakdowns and working well sub-themes, excludes recommendations) | Example Codes |
|----------------------|--|--|
| | Communication and collaboration working well (n = 30, 15.6%) | <ul style="list-style-type: none"> • communication between ISCs, providers, and families working well • communication has improved since switch • sharing of documents working well |
| | Lack of stakeholder accountability and oversight (n = 20, 10.4%) | <ul style="list-style-type: none"> • providers not held accountable • ISCs have no power if provider isn't following the Implementation Strategies |
| | Relationship with ISC working well (n = 18, 9.4%) | <ul style="list-style-type: none"> • unbiased perspective of ISC working well • good relationship with ISSA |
| Other | Other breakdowns (n = 78, 41.3%) | <ul style="list-style-type: none"> • ICAP funding mechanism is problematic • it's not parent-driven |
| | Everything working well (n = 53, 28.0%) | <ul style="list-style-type: none"> • all working well • all understandable • no breakdowns • no clarification needed |
| | Everything breaking down (n = 35, 18.5%) | <ul style="list-style-type: none"> • nothing working well • breakdown in most everything |
| | Other working well (n = 23, 12.2%) | <ul style="list-style-type: none"> • behavioral part working well • funding for services working well |