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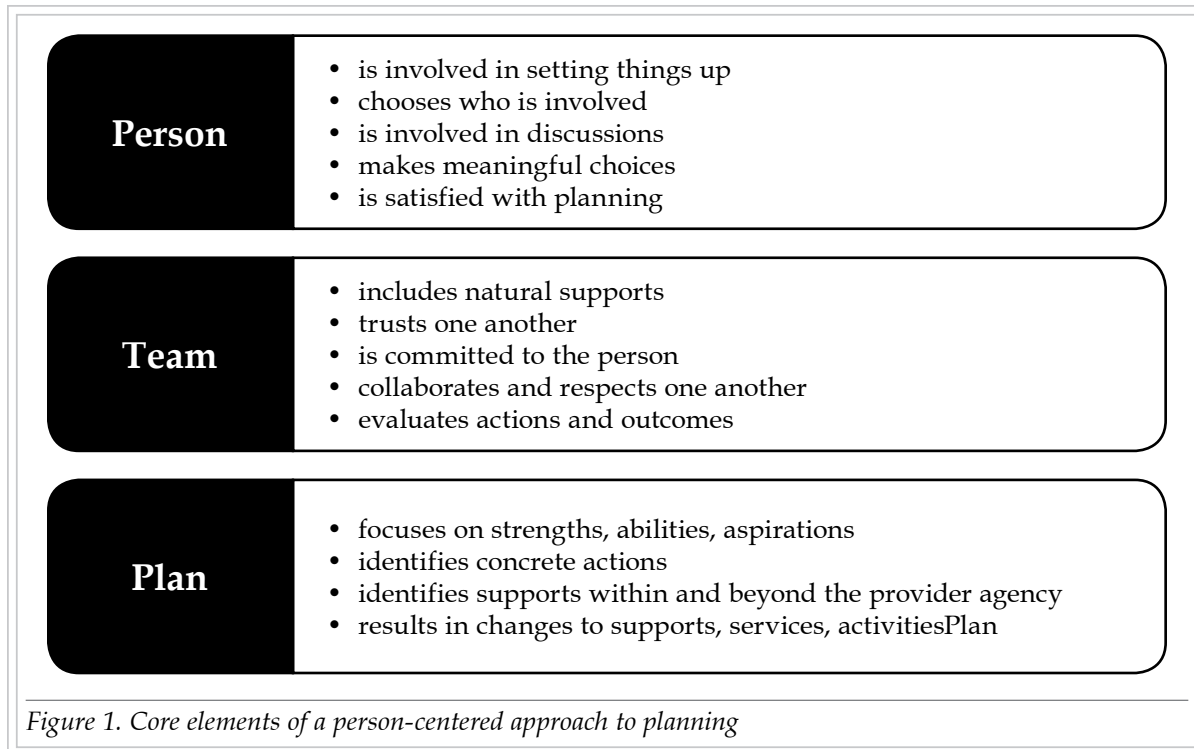   Kingston, ON

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Perspectives of Team Members on Person-Directed Planning

Abstract

Background: Recent legislation in Ontario promotes the use of person-directed planning (PDP) as a service to help individuals with intellectual and developmental disabilities (IDD) identify goals and the supports and services needed to achieve them. This study sought to better understand the lived planning experience of planning team members, including persons with IDD, families, staff, and planners/facilitators. Methods: A total of 48 individuals from eight planning teams were interviewed. Qualitative analysis was guided through use of a proposed framework for PDP; coding was expanded as needed. Results: Teams discussed the importance and challenges associated with the person having a voice and making choices; teams including the right people, who have the right attitudes, and engage in the right actions; and plans that focus on the person, identify concrete actions and supports to assist in the achievement of goals, and result in changes in the person's life. Conclusions: Team members discussed issues in a way that both aligned with, and expanded on, the conceptual framework for PDP, thereby reinforcing its utility in assessing the quality of planning.

In Ontario, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (Government of Ontario, 2008) calls for developmental services agencies to promote social inclusion, choice, and independence. In particular, this legislation refers to the use of person-directed planning (PDP) to "assist persons with developmental disabilities in identifying their life vision and goals and finding and using services and supports to meet their identified goals with the help of their families or significant others of their choice" (*Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act*, 2008, part 1, section 4.2). This legislation is among the first to use this term – the term person-centered planning (PCP) is more commonly used in other jurisdictions.

Over the last three years, planning practices in Ontario's developmental services system were studied through literature reviews, agency surveys, and meetings with stakeholders (see Martin, Ashworth, & Ouellette-Kuntz, 2012; Martin & Ouellette-Kuntz, 2011; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012a). This work revealed that a common set of core elements related to planning processes and teams are fundamental to individualized planning practices (see Figure 1; Martin & Ouellette-Kuntz, 2011). These core elements are based on values that stem from normalization (see, for example, principles described by Mansell & Beadle-Brown, 2004; key features described by Sanderson, 2000; and hallmark features described by Schwartz, Jacobson, & Holburn, 2000).

Person	• is involved in setting things up • chooses who is involved • is involved in discussions • makes meaningful choices • is satisfied with planning
Team	• includes natural supports • trusts one another • is committed to the person • collaborates and respects one another • evaluates actions and outcomes
Plan	• focuses on strengths, abilities, aspirations • identifies concrete actions • identifies supports within and beyond the provider agency • results in changes to supports, services, activitiesPlan

Figure 1. Core elements of a person-centered approach to planning

Such planning calls for the person with a disability to be involved in various aspects of the planning process and to have the opportunity to make meaningful choices. Planning team members must work collaboratively to focus on what the person wants, his/her strengths and abilities, and identify the supports needed to help the person achieve his/her goals. The team must also evaluate actions and outcomes as part of the commitment to supporting the person in achieving his/her goals (Martin & Ouellette-Kuntz, 2011). These core elements are common to the various approaches to individualized planning that have emerged over the last four decades (see O'Brien & O'Brien, 2000), and help to understand the principles on which good quality planning is based.

A survey of 156 developmental services agencies in Ontario (representing 72% of eligible agencies) revealed that a blended approach to planning is most often used (Martin, Ashworth, & Ouellette-Kuntz, 2012). In particular, agencies made use of one or more approaches (or tools) to plan for a single individual (Martin, Ashworth, & Ouellette-Kuntz, 2012). Results also identified that the core elements of planning were very much a part of the values that

underlie participating agencies, planning practices, with opportunities for meaningful choice and practices which focused on the person's strengths and abilities the most frequently mentioned by agency staff (Martin, Ashworth, & Ouellette-Kuntz, 2012).

In spite of having learned much about planning practices in Ontario's developmental services agencies, there remains limited information on the planning experiences of the people involved in the process – including persons with intellectual and developmental disabilities (IDD), natural supports, staff, and planners/facilitators. While knowing that organizations support planning processes that adhere to the core elements of person-directed planning is important to understanding the quality of planning, the perspectives of the individuals engaged in planning is essential. Therefore, this study sought to gain insight into how persons with IDD, natural supports (i.e., family and friends), staff, and planners/facilitators experience the planning process, as well as the extent to which perspectives differ across planning teams and types of participants. Findings from this study have the potential to inform the development of planning-related quality indicators.

Methods

Ethics approval for this study was obtained from the Research Ethics Boards at Lakehead University and Queen's University.

Recruitment

In the Fall of 2011, all developmental service transfer payment agencies in Ontario were invited to participate in an online planning survey that included a question on interest in participating in future planning-related research (Martin, Ashworth, & Ouellette-Kuntz, 2012). Recruitment for case studies began by contacting agencies who had expressed interest in future research. Interested agencies were asked whether an adult with IDD receiving support from their organization might be interested in having his or her planning team participate in the study. Agency staff then approached individuals (or substitute decision-makers) to gauge their interest and willingness to participate in the study. Those willing to participate were contacted by a member of the research team to schedule interviews, and often agency staff coordinated this on behalf of the research team.

We attempted to only include teams where every team member was willing to participate in the study. Prior to beginning the interview, each participant was provided with additional information about the study, an overview of the consent form, and an opportunity to ask questions.

Recruitment strategies considered geographic location, team composition (e.g., teams with only paid supports vs. those with both paid and natural supports), approach to planning (e.g., teams led by agency planners vs. independent facilitators), support needs of individuals with IDD (e.g., minimal vs. complex support needs), and language (i.e., a francophone team was recruited). As such, planning teams chosen were intended to represent, as much as possible, the scope of planning reality in the province.

Participants

Overall, 48 individuals across eight teams were involved in the case studies (see Table 1). Note that only four adults with IDD were inter-

viewed; the other four adults were unable to participate due to limited communication skills. Fifteen natural supports, 16 staff members, six planners (i.e., planning led by a member of the agency providing direct supports) and four facilitators (i.e., planning led by a person not employed by the agency providing direct supports) also participated. One team had no staff, and two consisted solely of staff.

In total, five women and three men with IDD were at the centre of the planning teams. Two of the individuals with IDD had significant support needs, while the others required only minimal supports. Two individuals had diagnoses on the autism spectrum, and one person had Down syndrome. One individual was blind, and another had very limited mobility. One individual was of aboriginal descent, and one person's first language was French.

Interviews

Before beginning interviews, the researcher discussed and noted basic demographic information for participants (e.g., age, sex, and geographic location). Additional information specific to the participant type was also noted, for example, the kinds of services received by persons with IDD, and the length of time agency staff and planners were employed in developmental services.

The interview focused on a number of planning-related issues, such as opportunities for choice and decision-making; frequency and nature of planning meetings; roles in planning; challenges; ways in which the individual is supported throughout the planning process; construction of the plan itself; and how the teams worked toward the identified goals. Interview guides (e.g., questions, probes) were designed to elicit information on participants' perspectives of their planning experiences. However, the results reported in this paper focus on a single open-ended question related to what individuals liked most or thought was most important about the planning process.

The interviews with team members were usually conducted over a two-day period. Team members were interviewed individually, though one consumer asked that someone be in

the room during their interview. In two cases, the consumer requested that someone attend the interview with them. Interview length varied from 20 minutes to one and a half hours. Interviews were audio-recorded to allow verbatim transcription for analysis, though the interviewers' field notes had to be used for analysis of two interviews due to a recorder malfunction.

Analysis

The interview was structured around pre-set research objectives (i.e., gain insight into the experience of the planning process). As such, a deductive approach to data analysis was employed. Specifically, a framework approach to coding interview data was used (Pope, Ziebland, & Mays, 2000). The five steps of the *framework approach* include (Pope, Ziebland, & Mays, 2000):

Table 1. Composition of Planning Teams

Consumers	Natural Supports	Staff	Lead
Sandra 25 Year Old Female Autism Minimal Support Needs	0	3	1 Planner
Christy 55 Year Old Female IDD Significant Support Needs	2	3	1 Planner
Laura 29 Year Old Female IDD and Blindness Minimal Support Needs	1	3	1 Facilitator
Chantal 30 Year Old Female IDD Minimal Support Needs	0	2	1 Planner
Paul 33 Year Old Male Down Syndrome Significant Support Needs	2	1	1 Facilitator
Tina 34 Year Old Female IDD Minimal Support Needs	1	2	1 Planner
Pierre 53 Year Old Male IDD Minimal Support Needs	2	2	2 Planners
Oscar 37 Year old Male Asperger Syndrome Minimal Support Needs	7	0	2 Facilitators

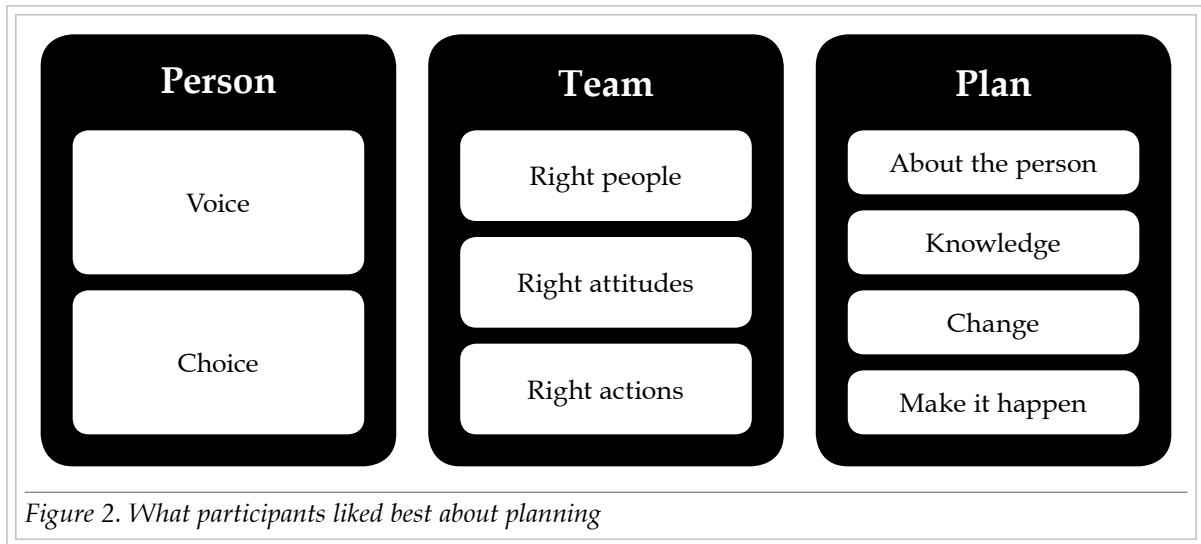| Person	Team	Plan
Voice	Right people	About the person
Choice	Right attitudes	Knowledge
	Right actions	Change
		Make it happen

Figure 2. What participants liked best about planning

(1) *Familiarization* – The authors immersed themselves in the data by reading the transcripts to become aware of key ideas (referred to as "codes"). Each researcher proposed different ways of understanding and summarizing the findings.

(2) *Identifying a thematic framework* – The authors then used the core elements of planning conceptual framework (Martin & Ouellette-Kuntz, 2011) as a guide for coding each of the questions.

(3) *Coding* – The authors independently coded the transcripts according to the conceptual framework, and expanded the framework as needed (i.e., created new codes). Then, the codes were reviewed to reach agreement, and supporting quotes were identified.

(4) *Organizing the index* – The authors organized the codes into major themes and sub-themes.

(5) *Mapping and interpretation* – The authors reviewed themes for each of the questions and explored the associations between themes to assist in explaining the findings. Themes were also reviewed within teams, as well as across participant types.

The analysis undertaken adhered to principles of naturalistic inquiry (see Lincoln & Guba, 1985), to ensure dependability (i.e., the interview questions were developed with several experts in the IDD field; four people conducted the interviews); credibility (i.e., many planning teams and types of team members were interviewed; more than one person coded the data;

agreement was reached on all codes and themes; researchers were very familiar with the data); and transferability (i.e., rich descriptions were provided for themes; direct quotes supported the coding categories; and all coding decisions were recorded throughout the analysis).

The frequency of themes identified was also analyzed by team and participant type.

Results

Overall Themes

The overall themes which emerged from planning team members' responses related to what they liked best about the planning process are illustrated in Figure 2. Note that quotes stemming from the francophone team are provided in French. In all cases, pseudonyms were assigned to each participant with IDD.

Two themes emerged related to the person: voice and choice. Planning team members spoke of the way that planning supported the person's voice. In particular, that the planning process allowed the opportunity for the person to not only be involved in discussions about his/her life, but also to express what he/she wants for his/her life.

Oh, it was good because it gave Oscar a chance to talk about what he really wanted. He had a list of goals that he had and everybody listened to him and talked about how they could help him with these goals … it gave

Oscar a chance to sort of … take charge of the meeting and to take charge of his life to let people know what his ambitions were. [Team1_natural2]

With respect to choice, planning team members talked about liking the way in which planning provided the person with the opportunity to make choices about his/her life goals and how to achieve them.

But she uh…it's, it's just trying to, to get her to take ownership of what she wants to do and um when she's always had things you know done for her you get used to that and you know it's hard maybe to think about where you want to go from there. For her I think that's part of the challenge is her figuring out what she wants to do next because someone has always told her what to do. [Team5_natural3]

Three themes were noted that had to do with the planning team itself. In particular, planning team members expressed that what they liked most about the planning process was that it allowed for the right people, with the right attitudes, and who engage in the right actions, to support the person to achieve his/her goals. The right people were those who were important to the person, included natural supports, and reflected the diversity of the people in his/her life.

… it was good that his brother and father – like his family was there. There were community people, family, friends. … I think that was really good; people of all different sectors of his life were involved. [Team1_natural1]

Pour moi personnellement j'adore rencontrer la famille. J'adore que la famille soit là et qu'ils supportent l'individu. [Team8_facilitator]

Team members who had the right attitudes were committed to the person, and showed respect and trust for him/her as well as other members of the team.

…everybody showed that they wanted to help Oscar and make his life better and do whatever it took to make his life easier. [Team1_natural3]

… But I know that I would trust whatever they said in support of him … or advice that they would give him. [Team1_natural4]

A number of subthemes emerged related to team members engaging in the right actions. These actions included:

Listening to the person and to each other:

Like how the people who have been in the meeting … how they'll still listen to what I offer up and say about what I feel. [Team6_staff1]

Empowering the person:

I think a big part of planning to me is helping the person get their voice out and express what it is they want so when people find out new things about them I think that's exciting. [Team2_facilitator]

Supporting the person to be involved in the planning process:

…but I think it was very good because you know it had set up in goals, like information that we talked about and then goals for Oscar, and then the visual factor that he had. I thought that was wonderful because he needed all of that – you know, the auditory and the visual and so on…But it was very well organized and his priorities and the visual map there I thought was excellent for Oscar … But it was all right in front of him and he could look at it and we could go back to it, which I think was really good for Oscar than just a lot of talk, per se – that he had something to follow and then he had this visual map that you know…and I think for Oscar too is that he can look at that and see things that he wanted. [Team1_natural1]

Being involved in the planning process and the person's life:

…where that person doesn't feel that it's just his parents that are helping him or making those decisions, that he's got other people involved and people there for support and ideas and so on. [Team1_natural1]

Communicating with one another:

Uh, what I like most is that we have open communication. We have regular contact with each other whether it's through emails, telephone calls and yeah, someone's always doing something. [Team5_planner]

Working collaboratively as a team:

I think we all knew you couldn't use a one-size fits all approach; but you almost needed to kind of go through

the process to realize it. So everybody's planning took a little bit of a different look. … So flexibility and versatility, I would say, would be the approach that we all agreed was the only way to go. [Team1_facilitator]

Supporting the person to achieve his/her goals by doing things and following-up on actions:

Mais l'affaire que j'aime le plus pour la personne elle-même c'est quand on a le plan d'actions et que les actions se font toutes faire. [Team8_facilitator1]

Everyone's doing things. So for example her play and support (friend) who you did get to meet, um, I was talking to her yesterday just following up with "did you have any play activities because I found this great thing on [Name of city] opportunity, do you want to get a hold of this person?" So I just gave her the name, number and all that information and then she followed up with it. So that we sort of complement each other and that, that really nobody is not doing anything. [Team5_planner]

Team members also discussed aspects related to plans, such as aspects of the planning process, the plans created, and the planning meeting. Here, four themes emerged, including: being about the person, knowledge, change, and making it happen.

Many planning team members most liked that the planning process was all about the person – his/her strengths, abilities, and aspirations; likes, wants, and needs; and his/her enjoyment:

My very favourite part of the whole interview is at the end of every section we get to talk about a dream. … what would you really, really like to see if you closed your eyes and think about what would happen in the next year. What would you really, really like to see happen? [Team3_staff1]

….pis tout le monde dit leur opinion, qu'est-ce qu'ils pensent serait meilleur pour Pierre, pis même ils marquent les choses qu'il aime pas aussi là, juste pour faire sa vie plus agréable. Mmmm. J'aime bien ce fait là, qu'ils prennent le temps de faire sûr que Pierre est bien .mmm dans sa peau, pis que s'il y a des problèmes qu'on peut mettre nos têtes ensemble et essayer d'aider pour faire sa vie plus plaisante. [Team8_natural]

Others liked that the focus was on the whole person:

It's almost, it's holistic. It's her entire world, her entire life and I think because they made it this way, it's good for her. It, everything, is intertwined; you can't separate her job from her family, from her friends, from just her life so there, it's all together and I think that that's the best thing for Tina. [Team7_natural1]

Many participants commented on how planning provided them with the opportunity to celebrate the person:

We start the planning process by inviting each person to say what they appreciate about the person. So we raise up their gifts first and that's likely my favourite part of the meeting. [Team3_staff2]

A second theme emerged related to knowledge. Here, planning team members spoke of how the planning process provided opportunities to share information and learn from one another, which helped to create a shared understanding among team members:

It, it catches everybody up and puts everybody on the same page as to what's been happening and has happened and…what direction we're heading. [Team4_natural1]

We can be the input, we can say things you know, there aren't many things we don't appreciate but we can sort of ask, ask questions if we're not certain why they're doing this thing a certain way or we can be a part of planning…. [Team4_natural2]

The third theme centered on the importance of change – how the planning process was outcome-focused and responsive to the needs and changing needs of the person:

… everything moves along smoothly and lots is happening for her… [Team5_natural]

I really like how person-centred it is, and that we have a new package called essential lifestyle planning package which I don't think is excellent but because we do personal outcome measures we're able to mesh the two together and when you assess somebody's desires under the 21 outcomes you don't miss stuff. And I like that we change things as they need to be changed. So we're in the process of changing our planning system so that it focuses completely on the person and their 21 outcomes. [Team7_planner]

Planning team members also appreciated how the plan itself allowed them to recognize the improvements in the person's life:

> *…because Christy, since she moved she changed um, towards better …million time like we cannot even believe…* [Team4_staff2]

The fourth theme focused on how planning enabled team members to make things happen for the person. In particular, it provided an organized way for them to identify the concrete actions and natural and formal supports needed to help the person achieve their goals:

> *It's very well done. They usually have a list of different things that they want to talk about…we just go through it and it's very well organized.* [Team4_natural2]

> *I like how it's all put together in one package that you can see it all um, all at once. And I love, my favourite piece we have of the plan right now is the page where it says all the people in Tina's life. So it's like a circle, it's a map and Tina is in the middle and then we put in there everyone who's in her life and how they support her in all these different ways and I love to see that when people have that full, and she has it quite full which is great.* [Team7_staff1]

In some instances, determining how to make things happen for the person called for the team to engage in creative thinking:

> *Basically it's, to me it's thinking outside the box. Finding out what her wildest dreams are, whether they're achievable or you know too farfetched to even imagine, they're put down in writing. And then they kind of set goals to have her achieve it.* [Team6_staff2]

Frequency of Themes by Team and Type of Participant

Table 2 shows the frequency of each theme by team and participant type. Findings revealed that different themes emerged across planning teams. While all themes (i.e., person, team, and plans) were brought up by several members of Team 1, Teams 2 and 5 focused mostly on aspects related to the team (i.e., right people, right attitudes, and right actions). Teams 3, 4, 6, and 7 primarily discussed issues related to plans (i.e., about the person, knowledge, change, and making it happen), while Team 8

equally emphasized issues related to the team and plans. Interestingly, Teams 4 and 7 did not mention aspects related to the person (i.e., choice and voice), and Team 3 made no mention of aspects related to the person or team.

Findings also showed that similar themes emerged across types of planning team members. In particular, the attitudes and actions of team members, and the importance of plans being about the person, were frequently mentioned by natural supports, staff, and planners/facilitators. However, consumers (i.e., persons with IDD) most often talked about issues related to the team, though they did mention issues related to plans; none of them mentioned issues related to choice or voice (i.e., the person).

Discussion

Through the case studies, we learned about what the people involved in planning think is most important about the planning process – and this lived planning experience appears to be in sync with the previously identified core elements framework (Martin & Ouellette-Kuntz, 2011).

As in the core elements framework, planning team members brought up issues related to the person, the planning team, and the plans that resulted from the process. Planning team members spoke of the importance of the person having a voice and making choices – aspects which are consistent with core elements related to being involved in discussions and making meaningful choices. Planning team members also took involvement a step further by saying that planning needs to provide the person with the opportunity to take ownership of what his/her life and supports should look like. Planning team members did not directly address elements of the framework related to choosing members or setting up meetings, nor with the person's satisfaction with planning. However, that is not to say that they were not addressed. For example, the importance of having the right people involved in planning was mentioned – and part of what makes them the right people is that they are the ones the person wants to have involved in their planning.

Table 2. Frequency of Themes Within Teams and by Participant Type

Themes and subthemes	Overall frequency	Frequency within teams								Frequency by participant type			
		1	2	3	4	5	6	7	8	Consumer	Natural support	Staff	Planner/Facilitator
Person													
Choice	5	3	1	0	0	1	0	0	0	0	2	1	2
Voice	9	5	0	0	0	1	2	0	1	0	4	3	2
Team													
Right people	9	5	0	0	2	1	0	0	1	1	5	2	1
Right attitudes	13	6	1	0	0	3	1	1	1	1	8	4	0
Right actions	32	11	6	0	1	8	2	1	3	2	13	8	9
Plan													
About the person	31	5	5	7	2	0	5	6	1	1	7	15	8
Knowledge	12	0	1	1	3	4	0	0	3	1	5	5	1
Change	8	2	0	0	1	1	1	3	0	0	3	2	3
Making it happen	11	3	0	1	1	0	3	2	1	0	4	6	1

Team members also spoke of issues related to the team itself, and the need for the right people, with the right attitudes, and who engage in the right actions to be involved in planning. The right people included natural supports. That team members had the right attitudes – trust, respect, and commitment, was important to planning. That team members engaged in the right actions during planning – for example, working collaboratively, evaluating and following-up on actions and outcomes, was also very important. Therefore, team members touched upon all aspects of the framework's team-related core elements. Other important elements were also mentioned by planning team members. Part of what made the right people right, was that they reflected the diversity of people in the person's life. For example, it is important to have friends from different areas of life involved (e.g., residence, church, activities). Right actions also included things like active listening – listening to the person and to each other; empowering the person to take owner-ship, use their voice, and make choices; supporting the person to be involved in planning (e.g., use of visual materials); open and frequent communication among team members; and being involved in planning, but also in the person's everyday life. All of these actions were deemed important for successful planning, and should be considered in evaluating the quality of planning.

Finally, team members discussed all aspects of the conceptual framework's 'plan' dimension – specifically how planning should focus on the person's strengths, abilities, and aspirations; plans should identify concrete actions and supports to assist the person in achieving goals; and the process should lead to changes in the person's life. Another issue related to plans, or the planning process, was noted. Team members spoke of the knowledge generated through planning as being an important part of the process – sharing information, learning from one

another, and learning new things about the person were also key to quality planning.

That the voice of persons with IDD is essential to good planning is well known and was echoed in this study by planning team members. It follows that the voices, or meaningful involvement of persons with IDD, in the evaluation of planning is necessary to truly assess the quality of the planning experience. In this study, we interviewed persons with IDD – some were able to participate and some were not. The persons with IDD who participated sometimes struggled with the questions and how to answer them. In particular, most individuals needed prompts and examples in order to understand the question, and some were still unable to answer even with multiple prompts and examples. The difficulties encountered in ensuring that persons understood the questions will certainly be important in the crafting of interview or survey questions that will form the basis of planning-related indicators. Therefore, this study not only provides preliminary evidence that the lived experience of planning is very much in sync with the values that underlie the planning process, it also offers useful information for the development of quality indicators related to the perspectives of the various people involved in planning.

Findings also revealed that some themes were more frequently mentioned among some teams compared to others. For instance, team-related issues (i.e., right people, right attitudes, right actions) were important aspects of planning for Teams 1 and 5, whereas Team 4 focused on plans (i.e., right actions). Planning is meant to be individualized – it is centered on and directed by the person; as such, it is not surprising that teams discussed different issues.

The frequency with which themes were mentioned was similar across participant types. In particular, having the right attitude, engaging in the right actions and focusing plans on the person, were frequently mentioned by natural supports, staff, and planners/facilitators. This finding shows that, regardless of team members' relationship to the person with IDD and their role in planning, they approach PDP in similar ways.

Conclusion

In-depth case studies of eight planning teams helped confirm the validity of the core elements of planning conceptual framework, thereby reinforcing these areas as important aspects of an approach to measuring the quality of planning. Specifically, it will be important to measure whether the person has a voice and choice in planning; that the right people, with the right attitudes, who engage in the right actions, are involved in planning; that plans are about the person, and that plans involve the creation of new knowledge and identification of concrete actions which result in change to the individual's life. The fact that these aspects of planning were noted as important by different types of team members (i.e., natural supports, staff, and planners/facilitators) further reinforces their importance in assessing the quality of planning.

Key Messages From This Article

Persons with disabilities: We need to hear what you think to make sure that you get the help you need to plan for your life.

Professionals: Person-directed planning (PDP) helps people identify their goals and the supports that they need. To assess the quality of PDP, the perspective of all people involved is needed on aspects related to the person, the team, and plans.

Policymakers: There are a number of core elements that underlie PDP that must be considered in the assessment of its quality. The quality of PDP cannot be assessed without hearing directly from persons with IDD, families, staff, and planners/facilitators.

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