MAPS
MULTIDIMENSIONAL ASSESSMENT OF PROVIDERS AND SYSTEMS

Understanding Planning Experience in Ontario through

Case Studies of Planning Teams

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Submitted to the Ontario Ministry of
Community and Social Services

June 30, 2013

MAPS (Multidimensional Assessment of Providers and Systems) is a research program to inform the assessment of services and supports for adults with intellectual/developmental disabilities in Ontario, Canada. MAPS (www.mapsresearch.ca) is supported by a research grant from the Government of Ontario's Ministry of Community and Social Services.

Enhanced social inclusion, choice and independence are outcomes central to recently passed legislation in Ontario – The Social Inclusion Act. The goal of MAPS is to achieve a consensus of what is meant by social inclusion and choice and how to best capture information about these outcomes.

MAPS is a provincial interdisciplinary team of researchers working with individuals with intellectual/developmental disabilities, their families, service providers, government representatives and researchers in other provinces and countries. The research team is led by Dr. Hélène Ouellette-Kuntz (Department of Public Health Sciences, Queen's University) and is composed of Dr. Virginie Cobigo (School of Psychology, University of Ottawa), Dr. Robert Hickey (School of Policy Studies, Queen's University), Dr. Rosemary Lysaght (School of Rehabilitation Therapy, Queen's University), Dr. Yona Lunsky (Department of Psychiatry, University of Toronto, and Research Head of the Dual Diagnosis Program at the Centre for Addiction and Mental Health), and Dr. Lynn Martin (Department of Health Sciences, Lakehead University).

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Suggested citation:

Martin, L., Ouellette-Kuntz, H., Petner-Arrey, J. & Walker, S. (2013). *Understanding Planning Experience in Ontario through Case Studies of Planning Teams.* [Kingston, Ontario, Canada]: Multidimensional Assessment of Providers and Systems (see www.mapsresearch.ca), Department of Public Health Sciences, Queen's University.

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Acknowledgements

This study would not have been possible without the participation of planning teams. The authors wish to thank organizations across Ontario who helped facilitate participation of planning teams, as well as the many participants who generously contributed their time, energies, and stories to help us understand planning experiences in Ontario.

The authors benefited from feedback and comments from MAPS co-researchers Virginie Cobigo and Robert Hickey. We gratefully acknowledge the invaluable research assistance by Melody Ashworth and Julie Rouette. We also thank Deborah Gorski, Asa Arrey, and Kristen Gorrell, who transcribed the interviews.

The study was undertaken as part of the Multidimensional Assessment of Providers and Systems (MAPS). MAPS (www.mapsresearch.ca) is supported by a research grant from the Government of Ontario`s Ministry of Community and Social Services. The views expressed in this report are not necessarily the views of all MAPS partners, researchers, collaborators or those of the Ministry.

Executive Summary

Over the last three years, planning practices in Ontario's developmental services system have been studied through literature reviews, agency surveys, and meetings with stakeholders. These efforts resulted in the identification of a common set of core elements fundamental to planning practices, touching upon aspects related to persons, teams, and plans. A survey of transfer payment agencies revealed that their planning practices closely adhere to the identified core elements. However, there remained limited information on the lived experiences of the people involved in the process – including persons with intellectual and developmental disabilities (IDD), natural supports, staff, and planners/facilitators. In response to this gap, case studies of individual planning teams were conducted over the last year.

A total of 48 individuals across eight teams were interviewed. These teams are representative of geographic location (i.e., northern, eastern, central, and south western regions), team composition (e.g., teams with only paid support vs. those with both paid and natural supports), approach to planning (e.g., teams led by agency planners vs. independent facilitators), and supports needs of individuals with IDD (e.g., minimal vs. complex support needs).

Qualitative analysis of interviews revealed much about what planning team members like the most and find the most challenging about the planning process –these were closely aligned with the core elements of planning. Specifically, teams talked about 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. In fact, several of the aspects that teams found most important about the planning process were also the ones that caused challenges. In particular, ensuring that the person has a voice and choice in the process, that team members engage in the right actions, and that plans lead to real changes were identified as difficult. Therefore, this study provides preliminary evidence that the lived experience of planning is very much in sync with the values that underlie core elements of planning.

Overall, the case studies helped to confirm the validity of the previously identified core elements of planning, thereby reinforcing these as areas that should be part of the approach to measuring the quality of planning. Because planning necessitates the meaningful involvement of persons with IDD, their voices must be heard to truly assess the quality of the planning experience. To this end, the case studies also enabled the identification of ways of asking people with IDD (as well as natural supports, staff, and planners/facilitators) about their planning experiences – all of which will be useful in crafting the survey or interview questions that will eventually form the basis of quality indicators.

It will be important to monitor planning successes and challenges at a system-level in order to really understand what actions can be taken to improve the quality and experience of planning, and consequently, the lives of persons with IDD.

Introduction

The Ontario *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (2008) calls for every service agency to promote social inclusion, choice, and independence. Person-directed planning (PDP) is named in the legislation as a service 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).

To do this, PDP focuses on helping persons with intellectual and developmental disabilities (IDD) establish and maintain meaningful relationships (Holbern & Cea, 2007) and on building community capacity (Albertson, Whitaker, & Perry, 2011; Sanderson, 2000; O'Brien & Lovett, 1992). Therefore, PDP is a process in which social inclusion is very much both a part and an outcome (Callicott, 2003).

Over the last three years, the process and experience of planning in Ontario's developmental services system was 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; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012b). The extensive review of the literature revealed a common set of core elements related to planning processes and teams (Figure 1) that are fundamental to individualized planning practices, such as person-centered or person-directed planning (Martin & Ouellette-Kuntz, 2011) and are based on an underlying set of values stemming from normalization (see, for example, principles described by Mansell & Beadle-Brown, 2003; key features described by Sanderson, 2000; and hallmark features described by Schwartz, Jacobson, & Holburn, 2000). Such planning calls for the person with IDD to be involved in various aspects of the planning process, including setting timing of meetings, choosing team members, setting goals, and making meaningful choices, and for planning that focuses on what the person wants as well as his/her strengths and abilities, and the supports needed to help the person achieve his/her goals are identified and implemented (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).

While individualized planning is common practice in developmental services, research on its effectiveness and outcomes remains limited. Among the relatively small number of studies that have been conducted, this type of planning has been associated with improved quality of life (Claes, Van Hove, Vandevelde, van Loon, & Schalock, 2010); improved social networks, community involvement, contact with friends, contact with family, choice, autonomy, relationships, and satisfaction (Cleas et al., 2010; Cooks & Abraham, 2007; Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004; Robertson et al., 2006); as well as long-term satisfaction with both planning processes and outcomes (Everson & Zhang, 2000). However, the extent to which it has 'really' led to inclusion has been questioned (Clement & Bigby, 2009; Robertson et al.,

2006). For example, an individualized approach to planning emphasizes use of informal and community-based supports, but the establishment of such relationships and supports is difficult for some (see review by Claes et al., 2010).

Figure 1. Core elements of a person-centered approach

The person
...is involved in setting things up
...chooses who is involved
...is involved in discussions
...makes meaningful choices
...is satisfied with planning

Team members
...include natural supports
...trust one another
...are committed to the person
...collaborate & respect each other
...evaluate actions and outcomes

Plans
...focus on strengths, abilities, & aspirations
...identify concrete actions
...identify supports within & beyond the provider agency
...result in changes to supports, services, &activities

A survey of 156 developmental services agencies (representing 72% of eligible agencies) revealed that, in Ontario, blended approach to planning are used– meaning that one or more approaches (or tools) to planning are often used to plan for a single individual (Martin, Ashworth, & Ouellette-Kuntz, 2012; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012a). Participating agencies also revealed that they collected a wide variety of planning-related information on all persons with IDD supported (Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012b) making the developmental services system well-positioned to implement standardized data collection of planning practices.

In spite of having learned much about planning practices in agencies in Ontario, there remains limited information on the planning experiences of the people involved in the process – including persons with IDD, natural supports, staff, and planners/facilitators. In response to this gap, case studies of individual planning teams were conducted to gain insight into how persons with IDD, natural supports (i.e., family and friends), staff, and planners/facilitators experience the planning process, and to inform the development of planning-related quality indicators.

This report describes findings from the case studies, giving voice to various individuals on the teams and learning by examining the unique and common features and experiences of persons involved in planning.

Methods

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

Recruitment

In the fall 2011, all developmental service transfer payment agencies in Ontario had been invited to participate in an online survey related to planning that included a question on interest in participating in future planning-related research. Recruitment for the case studies began with contacting those agencies that had expressed interest in future research. We asked whether an adult with IDD receiving support from their organization might be interested in having his/her planning team participate in the study. The staff from the agency approached individuals (or substitute decision-makers) to gauge their interest and willingness to participate in the study. Those willing were contacted by a member of the research team to schedule interviews; 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. When this was not possible, we interviewed as many team members as possible. 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 support vs. those with both paid and natural supports), approach to planning (e.g., teams led by agency planners vs. independent facilitators), and support needs of individuals with IDD (e.g., minimal vs. complex support needs). As such, the planning teams chosen were intended to represent, as much as possible, the scope of planning reality in the province.

Participants

Overall 48 individuals across 8 teams were involved in the case studies (see Figure 2). We interviewed six adults with IDD[1], 15 natural supports, 16 staff members, and nine planners/facilitators[2]. The largest team had ten members (with no paid supports) and the smallest team had three members (with only paid supports).

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, another had very limited mobility. One individual was of aboriginal descent, and one person's first language was French.

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[1] Two adults with IDD were not able to participate in the interview due to limited communication skills.

[2] The term "planners" refers to planning led by a member of an agency providing direct services/supports, while the term "facilitator" refers to planning led by a person not employed by the agency providing direct services/supports.

Figure 2. Description of planning teams

Interviews

Prior to the interview, the researcher discussed and noted some basic demographic information (e.g., age, sex, and geographic location) for each participant, as well as some additional information specific to the participant type. For example, participants with IDD provided information about the kinds of services they received and how long they had been receiving these services), while staff members provided information on the length of time they had worked in the agency and in developmental services.

The interviews focussed 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. The plan itself and how it was constructed was also discussed, as well as how the teams worked toward the identified goals. Interview guides were designed to elicit information on the participants' perspectives of their planning experiences. While the same major topics were included in all interview guides, questions were worded slightly differently .

The interviews with team members were usually conducted over a two-day period. Interviews took 19 minutes to 1 hours and 36 minutes per participant. All interviews were audio-recorded to allow verbatim transcription for analysis.[3]

This report focuses on two (2) questions related to general planning experiences (see below).

> - What do you like most about the planning process?
> - *What do you like the most about your planning meeting or plan?*
> - What do you find most challenging about the planning process?
> - *What don't you like about your planning meeting or plan?*

Analysis

Since our case studies data collection was structured around pre-set research objectives, a deductive data analysis method was used. Specifically, we applied a framework approach to coding interview data; an approach which is gaining credence in applied policy-relevant qualitative research (Pope, Ziebland, & Mays, 2000).

The five steps of the *framework approach* were followed (Pope et al., 2000):

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

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[3] Note that a recorder malfunction prevented the transcription of two interviews. In these instances, interviewer notes were utilized.

2) *Identifying a thematic framework* – The two first authors then used the 14 core elements planning as a guiding framework for coding each of the questions (see Figure 1; Martin & Ouellette-Kuntz, 2011).

3) *Coding* – The first two authors independently coded the transcripts according to the framework, and expanded the framework as needed (i.e., created new codes). Then, they reviewed the codes and supporting quotes together and reached agreement on codes (see "credibility" below).

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

5) *Mapping and interpretation* – The first two authors reviewed the 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), including:

- Dependability:
    - We developed the interview questions with several experts in the IDD field;
    - We used four different interviewers.
- Credibility:
    - We interviewed different types of planning team members (i.e., persons with IDD, natural supports, agency staff, agency planners, and independent facilitators);
    - We interviewed many planning teams (i.e., eight teams);
    - More than one person coded the data, and agreement was reached on all codes and themes;
    - Through prolonged engagement with the data, we became very familiar with it.
- Transferability:
    - We offer rich descriptions of each theme identified;
    - We provide direct quotes from the participants to illustrate coding categories;
    - Throughout the analysis, we recorded all coding decisions made.

Findings

The analysis revealed that much of what planning team members liked most and found most challenging about planning was closely aligned with the core elements of planning (see Figure 1; Martin & Ouellette-Kuntz, 2011). For this reason, the results are presented in relation to the core elements.

The themes are described and supporting quotes are provided for each of the questions posed. We also discuss the extent to which these themes were common to members of different planning teams and participant types (i.e., persons with IDD, natural supports, agency staff, and planners/facilitators).

What do you like the most about the planning process?

Figure 3 illustrates the link between the core elements framework (see Figure 1; Martin & Ouellette-Kuntz, 2011) and the overall themes emerging from planning team members related to what they liked best about the planning process. The frequency with which themes and sub-themes appeared overall, as well as by team and participant type is provided in Appendix A.

Figure 3. What planning team members like best about the planning process

Person

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.

> *It means giving them a voice. That's why I think planning is so important. Individuals have their own dreams, their own goals; and this whole planning process is about them.*

> *... this planning process is letting them have a voice, letting them be heard, and helping them plan and what needs to be done and it's great.*

> *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.*

> *Que lui, que Pierre a le…c'est son plan. Y dit qu'est-ce qu`y veut pis qu'est-ce qu'il aime, pis qu'est-ce qu`y n'aime pas et qu'est-ce qui veut dans sa vie…*

> *Well, I think the main thing for me was that it was Oscar's ownership…he was made to feel that this was for him and it was important what he thought and what he felt as opposed to so often, well, it's what other people feel is important for you.*

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. For example:

> *He had the support of everybody to vocalize what he wanted to have happen in his life, which I think was great.*

> *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.*
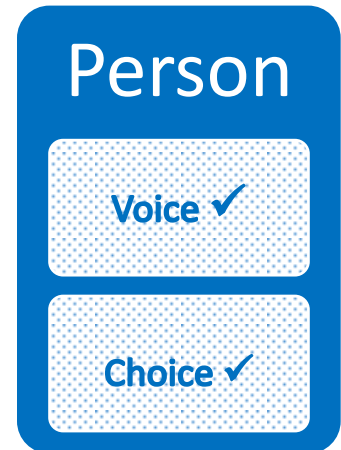
Team

Three themes were noted that had to do with the 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, who have 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.

Team

Right people ✓

Right attitudes ✓

Right actions

You know it's just a celebration and an opportunity for everyone that's important in her life to get together.

… 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.

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

…both were his teachers in school, but they also are members of the church that he belongs to, which he's very active in.

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.

Well, for sure I was happy to see all those people that were wanting to be involved in Oscar's life and to be able to help him succeed in his objectives or his goals.

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

…Ils sont intéressés à faire la vie de mon frère le mieux possible.

... others participate in the planning process but he's the focus point and it's respectful of him.

So all of us, you know, have a connection; and so it was very easy for people to talk and share, sort of like if you were around a Christmas table.

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

Team members who engaged in the **right actions** were also noted as being important to the planning process. This meant that team members:

Listened to the person and to each other:

> *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.*

> *Like how the people who have been in the meeting who considering I wasn't yet able to go, how they'll still listen to what I offer up and say about what I feel.*

> *Que la personne est entendue et que c'est centrer sur elle.*

Empowered 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.*

> *Um, I think with the Person Centered Planning what it did, was it reminded us that we have to make sure that the individuals have a voice. Um, it is about them. When we were doing like the more clinical ISP[4]s and that sort of stuff I think you kind of lost sight of that because it did seem to be more clinical and just….it seemed like completing some paperwork just to do some paperwork. Person Centered Planning has to be very person centered focus and it really is driven by the people that you are supporting.*

Team

| Right people |
| Right attitudes |
| Right actions ✔ |

Supported 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.*

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[4] ISPs=Individual Support Plans

…And the meeting was run in...language that he was able to understand.

Were ***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.

And I have to say that, all the family has been really good about coming and helping Paul get settled in the new house too…and you know everybody brought things…

Communicated 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.

... any questions you may have and communicating with one another because your days just get busy and you …sometimes you think oh I need to pick up the phone and…well just the other day that's exactly what I was saying to Laura as far as calling (friend) and you know give (friend) a call.

… I find them really helpful and I like to see…hear how Laura's doing in other areas 'cause she doesn't always volunteer that information. She's pretty quiet so it's good to hear from (friend) or you know (planner) to hear what's happening in her apartment if she hasn't been talking to me much lately, like if I just haven't seen her…

Worked ***collaboratively*** with one another and took a team approach:

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.

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

I like to be included. I like to be seen as someone who is instrumental.

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…

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.

Plans

With respect to plans - which include comments on specifics of the planning process, the plans created, and the planning meeting - four themes emerged: 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***.

Plans

About the person ✔

Knowledge

Change

Making it happen

It's usually identifying Tina's strengths and um, saying what she's good at and, describing her awesome personality and how easy going she is.

…the exciting part is that the goals now are much more connected to the dreams…

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? And it's so nice to be able to ask someone that question, not just Chantal but anybody um, and let them, let them go.

Well, it's not what we think she should do you know. It's just from knowing her and knowing the things that she enjoys you know making the plans for what will give her happiness and joy and what she'll enjoy…It's not always what we think she should do it's what she'll enjoy doing.

….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.

Others liked that the ***focus was on the person*** – the ***whole person***, and how the team's approach was ***individualized*** to suit the needs and preferences of the person.

… You can do the most wonderful plan but if it doesn't connect to the individual and if the person is not really engaged then of course it's not going to, it's not going to stick, it's not going to work because it's about anyone but them…So, what I like most about it is the focus being Paul and then working from there around that and really trying to engage others in the planning process and engage them in the implementation of the action.

…and I love how the review is set up in the different sections and how we kind of go through each area of her life and talk about what's important to her.

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.

I like the fact that everyone comes together for two hours we only talk about Paul.

So it can be varied according to what the individual chooses – what tool they want to use and what's most helpful to them - so very individualized.

Many commented on how planning provided them with the opportunity to **celebrate** the person.

The celebration of the person likely. 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.

You know it's just a celebration and an opportunity for everyone that's important in her life to get together.

Others liked how the process reminded them of the importance of **empowering** the person.

But also in the room when you do the planning session, if it's done well, there's a lot of empowerment and I like that. I mean, I like to see the person celebrated as a person and to have them feel power. Because a lot of these people don't feel very powerful; and for them to be the focus and to feel that kind of, "I can do" attitude is really valuable, so I like that part of it.

Whereas this planning process is letting them have a voice, letting them be heard, and helping them plan and what needs to be done and it's great. It's working individually with them.

A second theme emerged related to **knowledge**. Here, planning team members spoke of how the planning process provided the opportunity to **share information**, **learn more** – and sometimes **learn new things** about the person; from this emerged 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.

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.

On apprend à les connaitre plus....Pierre je le connais ben beaucoup là, je sais comment y se sent… on le connait plus, pis ses rêves qui nous a jamais dis de même…

Plans

- About the person
- Knowledge ✔
- Change
- Making it happen

Team members also liked how the planning process allowed them to **learn from one another**:

> 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…

> I think it's nice to *hear the feedback of other people.*

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 persons.

> *… everything moves along smoothly* and *lots is happening for her…*

> 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.*

Team members also spoke of how they liked the way that the planning process led to ***connections with the broader community***.

> The church is a very good group for him because *he does things and they appreciate it.*

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…

Plans

- About the person
- Knowledge
- Change ✔
- Making it happen

The fourth theme focuses on how planning enabled team members to **make things happen** for the person by providing an ***organized*** way for them to ***identify the concrete actions*** and ***natural and formal supports*** needed to help him/her achieve 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.*

Plans

- About the person
- Knowledge
- Change
- Making it happen ✔

It puts words; it's a process that's a bit easier instead of leaving everything scrambled up in your mind. It sort of puts you in a process which is good…

… He had a list of goals … and everybody listened to him and talked about how they could help him with these goals.

I'm not responsible for…for everything and so it's great for me to know that she's being looked after by this person, and this person's going this day…you know and so I can sit back and say ok, I, I know she's totally…totally ok …

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.

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.

The 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), and Teams 3, 4, 6, and 7 primarily discussed issues related to plans (i.e., about the person, knowledge, change, and making it happen). 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.

The 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; no one mentioned issues related to choice or voice (i.e., the person).

What do you find most challenging about the planning process?

In questioning team members about the challenges of planning, the same general themes emerged (see Figure 3). Namely, they spoke of challenges related to the person (i.e., voice and choice), the team (i.e., right people, right attitudes, right actions), and to the plans (i.e., about the person, knowledge, change, and making things happen), though some new themes emerged. Figure 4 illustrates the overall themes emerging from planning team members related to what they found most challenging about the planning process. The frequency with which themes and sub-themes appeared overall, as well as by team and participant type is provided in the Appendix B.

Figure 4. What planning team members find most challenging about the planning process

Person	Team	Plans
Voice	Right actions	Change
Choice		Resources

Person

Two themes emerged related to the person: voice and choice. Team members discussed the difficulties associated with the person finding his/her **voice** and ***expressing what he/she wants*:**

> *With Laura the biggest challenge has been getting her to take ownership of what she wants. She's very laid back, she's not quiet but she doesn't say much. But when she does…I mean she gets the giggles very easily so I'm sure you'll have a great time talking to her. It's just trying to, to get her to take ownership of what she wants to do and 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. …or done it for her without telling her and so now we're trying to get her to take ownership and you know with the challenge of having an intellectual disability there or learning disability, whatever it is with Laura, on top of having her vision loss you know that's been the biggest challenge, getting her to you know set goals and take ownership.*

Team members also talked about how it could be difficult to ***involve the person*** in planning:

> *And then building on there and just finding…trying to find out what that is. Laura is great, well I mean…I'm just thinking that you know sometimes it's very challenging to find out because the communication may not be there for finding out exactly what that person is wanting or needing or, you know, wanting to do or assistance needed , so sometimes that is a challenge in itself …*

> *It can be challenging at times because some people that I have supported are non-verbal, some don't even have the concept of why they're there. They don't have focus, some don't have dreams; they have been told so many times that they can't do something that when you try to approach it in a different way they'll be like no I've already done that it didn't work. They just, they have low self-esteem, so it's, sometimes it's challenging to get beyond that and you know help them dream. …*

> *Yeah, sometimes maybe the goals that are presented are, are the kinds that he might not understand fully so, probably sometimes he is not completely aware of how important it is and, and what, what it means…*

A consumer also commented that ***uncertainty*** made it difficult for her to be involved in planning:

> *I get nervous `cause I don't like…`cause I don't know what kind of stuff they'll say.*

When persons were involved in the planning process, team members sometimes struggled with **_understanding_** exactly what it was they wanted:

> *I guess in, in another thing for me in putting their reviews together is I always am thinking when I'm going through the process…did I actually find the really important things? Have I really, have I really been able to, you know, hear from Chantal the most important things in her life?*

> *Moi ça serais…des fois on dirait qu`y  sait pas ce qu'il veut là. Comme, c'est dur de trouver quelque chose qu`y va aimer…*

Related to **choice**, team members spoke of the difficulty in **_knowing if the goals were really those of the person_**:

Person

Voice ✔

Choice ✔
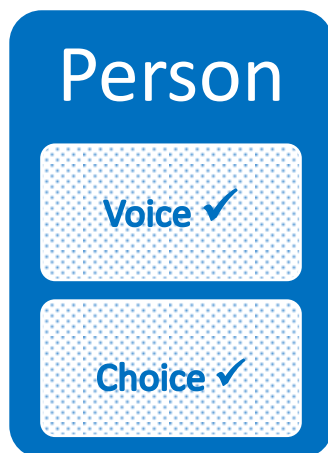
> *… she has a small idea of what she wants but for her to have ideas of different things to try to achieve, different goals to set, she has a little bit of a, a problem with figuring out what she wants to do. Like even spare time, if you say what would you like to do in your spare time? Sandra has a hard time trying to figure out what she likes to do, believe it or not. So then you're kind of, it's not that you're leading her or coaching her, you're kind of having to give her some options. She's really great at, when you have options that she can either say yes or no. But it's kind of her imagination of what is achievable isn't as broad as some of our other people we support.*

> *… I think Sandra maybe struggles to come up with goals, so sometimes that can be challenging trying to make suggestions but not have Sandra say yes I'll do that. It's more giving her a lot of suggestions but giving her time to, to really process it and come up with goals that she actually wants instead of someone else just cause they suggested it.*

Also, it was sometimes difficult for team members when the **_person made decisions that they disagreed with_**:

> *So sometimes that concerns me and maybe where we'll make suggestions for her benefit, her stress level and her anxiety level that maybe she doesn't really want to take on board so those times maybe there could be a compromise in her plan because it is for her benefit. So it can be challenging that way where if you really feel there's something that would help her but she does not want to consider it then it's not in. But if there's a way…sometimes that's challenging.*

Team

While individual team members made mention of issues related to having the right people (i.e., natural supports, diversity of members) and the right attitudes (i.e., commitment, respect), overwhelmingly they discussed challenges to engaging in the **right actions**. In particular, team members noted difficulties associated with:

Involving natural supports and ***managing conflict*** during planning:

> Very much, and there's *a lack of family…I don't know if it's all across the board in developmental services, but I know the groups we work with, there's a lack of family involvement.*

> *…* sometimes *the meetings tend to be about the family and not about the individual. They kind of take that turn. …* And sometimes *the family gets more focussed on what their needs are* and *what they think the person should have as opposed to what the person wants.*

> *...* It's often times *family dynamics* can come into play or people feel they would like this for their family member, let's say, which isn't always what the individual may want. So as a facilitator, trying to get what the person wants is the most important thing, *not what everybody else may think they want for the person. …*

> *…* So *families pay you to provide a service.* It's not really sometimes the person that's paying you. It's their parents. …*So who are you reporting to?* You're getting paid by a parent and you're providing the direct service to the client, and they're paying you. It sometimes can be a *tricky situation.*

> *…So I think the hardest part is trying to – you have to keep reminding yourself the client is the person with the disability, but still *having to be mindful that the supports in his life are…he's going to need to call on those supports. So it *has to work as well within the family context*, if that makes sense. …You have to pull everybody together so it can't be a sort of…you can't set up a confrontation.* So it's *striking that balance I think between the needs of the person and the family.*

> I had a bit of a challenge with (a family friend) … like for many years she wanted to have her son and Oscar and (friend) and maybe some of the others live together in a group – sort of like a group home. … I know in her mind she was – I don't think she…*she wasn't happy when Oscar came into the condo and the plans to come in, because that then affected her plans.....* So I wondered about including her in it because I know that *she was negative about it*, at least about the condo aspect.

Communicating and ***collaborating*** with one another:

I guess the problem can be sometimes getting those people around, you know challenges to our time … people are all over the place; we have had plans when people have attended via conference, or Skype and stuff which is you know is nice and it's not quite as nice as having everyone in the room kind of thing.

> *…So people might think that she's the boss or she's the go to … and sometimes people think your role is more than it is because I call the meetings and host the meetings doesn't mean that at the end of the day I'm responsible for this person. …we all have to work together.*

> *About the process itself, the hardest part about it is trying to get all the people that need to be in the room, in the room. … We had 21 people at the first meeting to make this happen. So there were people from all kinds of community organizations - CCAC, Helping Hands, the Association for the Physically Disabled, VON, people from (provider agency), physio, OTs, the people that own the apartment building that he was going to rent an apartment from .... it's really hard to schedule and get all those players in one place.*

> *I guess one of the things I found, it went too slow. My comfort level – I was thinking this is a slow process. I would've liked to have seen it bang, bang, bang, bang. There's the problem. There's the solution. … I guess that was my biggest challenge. … It just seemed; I thought it could've been done a lot faster. That was my perception. What's wrong? There it is. That's the problem and now we have to have the solution.*

Doing things for the person and ***following-up*** on actions:

> *Sometimes as the facilitator of the process, the challenge is holding people to, to tasks at some point. So it's you know not only do we have the meeting and with all the meeting minutes I usually have ok, what are people doing? Whether it's subliminally or sort of thrown in there in the meeting minutes, when you review the meeting minutes you're kind of gonna have that reminder of what to do and again sometimes following up, like over emails and it's sort of like when you're facilitating you're on them, you're the big cheese even though you're really not.*

> *There were things that people were going to help him with something like that. Did it happen? I don't know. I know he has been to see (a family friend) a few times and I know that we talked a bit the other evening about what she had planned for him – or not, she didn't plan it for him, but her job was to help him plan – but I don't know how far that got either. … Yeah. I'd like to know if any of this happened.*

Team

Right actions ✓

Plans

Two themes emerged with respect to challenges with plans or planning. Team members noted difficulty with plans leading to real **changes** in the person's life:

> *When something falls through, like if , like say for this, this one we're at right now, this team, this goal for Sandra, it's like, it's taking so much longer than it should really ...we got the application in but we haven't heard anything back so it's challenging when other things are preventing us from getting her towards that.*

> *...y'est ben particulier dans les choses qu`y aime ou qu`y aime pas alors des fois c'est pas disponible dans notre communauté.*

> *Well for the person..., finding home, very, very challenging because what they`re looking for in an apartment, and that, are not always available. That part has been very hard.*

Team members also discussed challenges related to the **resources** available for planning. In particular, they noted difficulties associated with:

Time:

> *Well generally it's, it's the time. I'm one person doing my role for all of [name of region] and I have a hundred and...and I'm not complaining at all...you know 150 people on my caseload and, a lot of those are in [name of city], a lot of them are out in the community and a lot are out of the district. So there's, there's a real challenge that way especially when you are trying to plan with another agency on how you know...if it's in town I might be away. I was away for 5 days last week and if there had been a planning meeting I would have missed that, you know. Although there's usually another staff person around who can fill in and, and, and we're good between (planner) and (work)...and the staff at (work) we're all good at communicating with each other. But that can be part of the big challenge is when do you find the time ...*

Money:

> *Another challenge just in the whole planning process is just the whole funding part of it as well. Anyways, funding's always a big issue, you know, for families to obviously pay for a facilitator to go through that process. It's difficult. Money's not always there, funding's not always there. So that's difficult.*

> *L'argent. Parce que nos gens qu'on supporte ont pas beaucoup d'argent. Ou c'est des petites pensions et toute coute beaucoup d'argent donc pour faire une activité y'a des couts.*

Language and cultural barriers:

> *Say if I do a plan for someone who's Arabic speaking and you know and to suggest resources or things in the community you know again in that case someone afterwards went to look it up on line you know different settlement agencies and things like that...I think we're talking about that in general and making connections. We have a diversity person who's you know trying to make connections with different agencies and stuff. We`re talking about connecting with them so you know and if it is another language to having an interpreter but then also you're writing it up, I mean you have an interpreter at the planning session but the plan`s written in English that's really not going to help people with the follow-up …*

Technology:

Plans

Change

Resources ✔

> *The current system we have right now, the plan is on paper so quite often you are waiting for it to be typed, waiting for it to come back so there's a bit of a disorganization piece for what you will. Uh, but we are in the process of changing that which is great. …Yes, this agency has ...Management System... so it's internet based; you can type in data into this information system, they're going to set the plan up on there as well. So every time we have a little blurb we don't have to wait to write it on a piece of paper, we can put it into the system which will print out a whole plan with all of the information current on it which is great. So that's really the only thing I find is the most annoying at this point is the writing on paper and the worries of losing the paper or not getting all the right information up to date, that kind of stuff.*

In terms of challenges associated with planning, different themes emerged **across planning teams**. Only three teams (i.e., Teams 1, 2, and 6) brought up issues related to each of the three themes (i.e., person, team, and plans). Teams 3 and 8 did not bring up challenges related to the team (i.e., right actions), Teams 4 and 5 did not mention challenges related to the plan or planning (i.e., change and resources); and Teams 4 and 7 did not bring up challenges related to the person (i.e., choice and voice). Teams 1, 4, and 5 focused most heavily on challenges related to the team (i.e., right actions).

The findings also showed that different themes emerged depending on the **type of planning team member**. Natural supports brought up issues related to each theme, while planners/facilitators focused most heavily on aspects related to the team (i.e., right actions). For staff, challenges related to the person (i.e., choice and voice) and team (i.e., right actions) were discussed most frequently. Only one consumer identified challenges with the planning process – it focused on having a voice in that process.

Discussion

Through the case studies, we learned that the lived planning experience appears to be in sync with the core elements framework (see Figure 1; Martin & Ouellette-Kuntz, 2011). Specifically, teams talked about the importance of the **person** having a voice and making choices; though they did not bring up aspects related to the person's involvement in choosing members or setting up meetings, nor with the person's satisfaction with planning. Team members also spoke of how **teams** needed to include natural supports, as well as members who trusted and respected one another, worked collaboratively, were committed to the person, and evaluated or followed-up on their actions and outcomes – touching upon all aspects of team-related core elements. Finally, team members discussed all aspects related to **planning** and **plans** – 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.

Many of the aspects of planning related to the **person** that team members most appreciated were also ones that caused challenges. While the person's *voice* was named as an important part of the planning process, team members noted that it was hard for some persons to express what it was they wanted for their lives, be it due to a lack of experience of being in control of their own lives, communication difficulties, or limited understanding of the planning process. Because of this, it was often difficult for team members to know whether they had managed to elicit what the person really wanted, or what was really important to him/her. Similarly, team members acknowledged the difficulties some persons experienced in making *choices* and questioned whether choices made were really those of the person, and not made to make others happy. Finally, the conflict arising when team members disagreed with the choices made by the person was also noted as a challenge to promoting choice in planning.

There were also several aspects related to **teams** that participants discussed as being both important and challenging. For example, knowing that it is important to *include natural supports* on the planning but that it is not possible for all persons, and *managing dynamics and conflicts* to balance between the needs of the person and those of the family. *Communication* and *collaboration* were also important, but managing schedules and different approaches or ways of working also created challenges. Last, the need for team members to show their *commitment* to the person and *do the things they said they were going to* do was seen as key to planning, but it could be very difficult for some to follow-through.

Lastly, team members spoke of the importance and difficulties encountered with respect to **plans** leading to *change*. Specifically, team members noted the importance of plans leading to improvements in the person's life, but also how some things remained out of their control. For example, no plan - no matter how well thought out or detailed - can help the person achieve their goal of moving into their own apartment if no suitable option exists in the community.

Naturally, some issues were more important to some teams than others. As an example, issues related to the team (i.e., right people, right attitudes, right actions) were both the most important and most challenging aspects of planning for Teams 1 and 5, whereas Team 4 often talked of aspects related to plans as being most important and most frequently brought up

team-related challenges (i.e., right actions). Because the planning process is meant to be person-centered or person-directed, it is not at all surprising that teams brought up different issues.

However, there was much similarity between types of team members as to the most important parts of the planning process. Specifically, having the right attitude and engaging in the right actions and focusing plans on the person were frequently mentioned by natural supports, staff, and planners/facilitators. However, there were some differences in terms of what the different types of team members thought was most challenging about planning. Issues related to the person (i.e., voice and choice) and team (i.e., right actions) were most often named as challenges by staff, while planners/facilitators mostly talked about difficulties with teams engaging in the right actions. Natural supports, however, brought up challenges related to all themes (i.e., person, teams, and plans). Again, these findings are not altogether unanticipated. In particular, given that staff and planners/facilitators often take a lead role in organizing and setting plans into action, it is not surprising that they were challenged by team members not engaging in the right actions. Compared to the other groups, natural supports most often mentioned issues related to the person having a voice and choice and teams having the right people with the right attitudes involved as most important – they have much invested in the person and in having the right people supporting him/her.

While consumers were interviewed, many struggled with the questions and how to answer them. In particular, most needed several prompts and examples in order to comprehend – though some were unable to answer even with these. 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.

Conclusion

The in-depth case studies helped to confirm the validity of the previously identified core elements of planning (see Martin & Ouellette-Kuntz, 2011 and Figure 1 of this report), thereby reinforcing these as areas that should be part of the 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 who have the right attitudes and engage in the right actions are involved in planning; and that plans are about the person, and through the creation of new knowledge and identification of concrete actions, result in change in his/her life.

Because planning necessitates the meaningful involvement of persons with IDD, their voices must be heard to truly assess the quality of the planning experience. To this end, the case studies also enabled the identification of ways of asking people with IDD (as well as natural supports, staff, and planners/facilitators) about their planning experiences – this information will be useful in crafting the survey or interview questions that will form the basis of quality indicators.

This study provided not only useful information for the development of quality indicators, but also preliminary evidence that the lived experience of planning is very much in sync with the values that underlie the planning process as intended by the Ministry. However, in supporting person's voices and choices, there are a number of challenges that arise as planning teams work toward the person`s goals and dreams. For this reason, it is important to understand and monitor at a system-level the planning-related successes and challenges – only with this knowledge and understanding can actions be taken to improve the quality and experience of planning.

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Appendix A

Frequency of themes within teams and by participant type: Like most about the planning process

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
Plans													
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

Appendix B

Frequency of themes within teams and by participant type: Challenges in the planning process

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	4	1	0	0	0	1	2	0	0	0	1	2	1
Voice	7	0	1	2	0	2	1	0	1	1	0	6	0
Team													
Right actions	18	6	1	0	4	4	1	2	0	0	2	8	8
Plans													
Change	4	1	0	0	0	0	2	0	1	0	1	3	0
Resources	6	1	1	1	0	0	0	1	2	0	1	2	3