

## Partnering for Research in the Field of Intellectual/Developmental Disabilities – Lessons For Participant Recruitment

### Abstract

*The importance of including persons with intellectual and developmental disabilities (IDD) in research is widely recognized, yet recruitment is difficult and participation rates are low. In this paper, the recent efforts of a province-wide partnered research program – the Multidimensional Assessment of Providers and Systems (MAPS) – are used to further the discussion of research recruitment to benefit adults with IDD in Ontario and elsewhere. Specifically, we report on six studies that utilized different recruitment methods (i.e., by researchers, through a third party, or based on previous study participation) with participation rates ranging from 17% to 94%. We found that service providers and funders play a critical role in promoting participation in research to ensure that persons with IDD and their families are represented. Practical suggestions are offered for researchers to more actively seek partnerships with providers and funders to increase, not only the success of their study, but also the relevance of their work.*

The importance of including persons with intellectual and developmental disabilities (IDD) in research in order to afford them the benefits of knowledge gained through such endeavours is recognized internationally and promoted by organizations like the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD; see [www.iassid.org](http://www.iassid.org)). IASSIDD, as well as national research organizations, have established guidelines for the ethical conduct of research to ensure the protection of vulnerable populations (Dalton & McVilly, 2004; Canadian Institutes of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC), and Social Sciences and Humanities Research Council of Canada (SSHRC), 2010). Notwithstanding the benefits of such guidelines, McDonald and Keys (2008) argue that research ethics boards limit access to community life by persons with IDD when they unduly restrict their involvement in research. They call for best practices specific to including adults with IDD in research.

Researchers have highlighted additional concerns about effectively recruiting persons with IDD into research. Such concerns include attitudes of gatekeepers (e.g., service providers, parents) which may limit access to potential participants, and difficulties communicating the purpose of the research simply (Swain, Parish, Luken, & Atkins, 2011; Cleaver, Ouellette-Kuntz, & Sarkar, 2010). To better allow for the development of strategies to facilitate improved participation, Cleaver and colleagues (2010) recommended clear and concise reporting in research articles of participation in research with and about adults with IDD. In particular, researchers should specify the

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methods by which participants were recruited (e.g., through researcher vs. third party) and consent was obtained (e.g., from the person vs. substitute decision-maker), as well as on the invasiveness of the procedures used to collect the data (e.g., interviews vs. blood samples).

In this paper, the recruitment methods employed in various studies undertaken in a recent province-wide partnered research program – the Multidimensional Assessment of Providers and Systems (see [www.mapsresearch.ca](http://www.mapsresearch.ca)) – are described to further the discussion of research recruitment of adults with IDD and their natural supports (e.g., family, friends) in Ontario and elsewhere. The value of partnering, defined as “establishing a long term win-win relationship based on mutual trust and teamwork, and on sharing of both risks and rewards,” (BusinessDictionary.com) to maximize participation in research is also discussed.

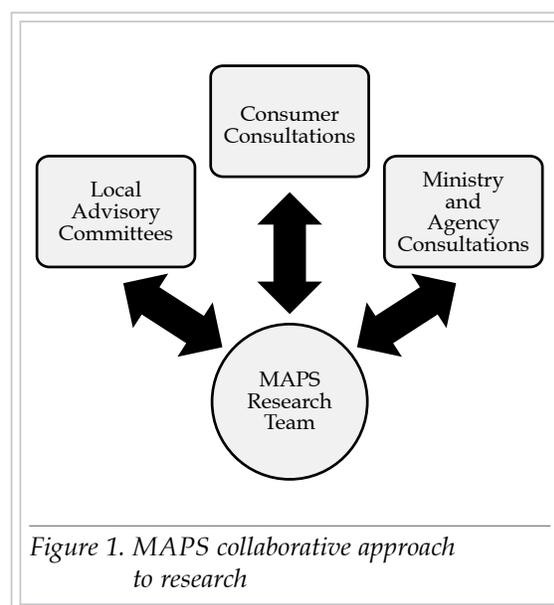
### Multidimensional Assessment of Providers and Systems (MAPS) Research Program

The Multidimensional Assessment of Providers and Systems (MAPS) research program (funded by the Ministry of Community and Social Services, or MCSS) aimed to inform the assessment of services and supports for adults with IDD in Ontario, and provided the MCSS with a set of indicators that could be used to assess the quality of supports and services. To this end, the provincial interdisciplinary team of researchers worked with individuals with IDD, their families, service providers, government representatives and researchers in other provinces and countries on numerous projects (see [www.mapsresearch.ca](http://www.mapsresearch.ca)). Many of these projects required use of empirical data collected from various types of research participants, who were recruited from multiple sources using several different approaches.

Throughout its work, the MAPS team employed a collaborative approach (Figure 1), consulting with persons with IDD and their families and representatives from service agencies and MCSS. Three times a year, the MAPS team met with persons with an interest in the program of research, such as persons with IDD, family members, service providers, and representatives of the MCSS, henceforth referred to as “stakeholders.” Through our Consumer Consultations infra-

structure, adults with IDD from four communities in three regions of the province contributed to the MAPS program: Central Region (Toronto), Southeast Region (Kingston and Kemptville), and North Region (Thunder Bay). Our Local Advisory Committees included family members of individuals with IDD, service agency directors or delegates, and representatives of MCSS in Kingston, Toronto and Thunder Bay. Once a year, the MAPS team also met with representatives of MCSS, including branch directors, managers, and policy analysts, and representatives from the regional offices. These consultation structures provided the MAPS team with a unique opportunity to discuss research protocols in development, present interim research findings and receive feedback on their relevance to Ontario with regard to the life experience of adults with IDD and their families, as well as to policy and service delivery. MAPS maintains an active website with posting of brief research updates (see [www.mapsresearch.ca](http://www.mapsresearch.ca)).

In this paper, the MAPS experience is used to examine various issues related to recruitment and participation of adults with IDD and/or their parents in three MAPS studies: (1) Parents Seeking Adult Developmental Services for their Children, (2) Understanding the Experience of Person-Centred or Person-Directed Planning in Ontario, and (3) Maximizing Social Inclusion, Choice, and Independence through Productivity Options. The goals and approaches for each study are briefly described below.



## Parents Seeking Adult Developmental Services for their Children (aka Parent Study)

To learn about the experience of parents requesting services in the context of the newly established application process across the province in 2011, we designed a three phase study involving the completion of a mailed survey and telephone interview by parents (Phase I), with the option of ongoing follow-up every three months (Phase II), and in-depth face-to-face interviews (Phase III) (see Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013a; Ouellette-Kuntz, Lunsky, Blinkhorn, Robinson, & Tint, 2013b; Saaltink & Ouellette-Kuntz, 2013).

## Understanding the Experience of Person-Centred or Person-Directed Planning in Ontario (aka Planning Study)

This study sought to better understand person-centred or person-directed planning in the Ontario developmental services system. We designed a two-part study that involved email surveys of planning practices completed by staff in developmental services agencies providing support to adults with IDD (Study I) and in-depth face-to-face interviews with members of planning teams – including persons with IDD, natural supports, paid supports (i.e., developmental services agency staff), and planners/facilitators (Study II) (see Martin, Ashworth, & Ouellette-Kuntz, 2012; Martin, Ouellette-Kuntz, Cobigo, & Ashworth, 2012; Martin, Ouellette-Kuntz, Petner-Arrey, & Walker, 2013).

## Maximizing Social Inclusion, Choice, and Independence through Productivity Options (aka Productivity Study)

The goal of this study was to create a snapshot of the range and nature of outcomes achieved in the area of productivity for social assistance recipients with IDD, and how these outcomes vary based on region, urban/rural residency, age and gender (Phase I), and to provide insight into how services are used and perceived, and how service recipient characteristics and service use contribute to the outcomes achieved (Phase II) (see Lysaght, Ouellette-Kuntz, Cobigo, & Petner-Arrey, 2013).

## Method

Projects were reviewed and approved by Queen's University Research Ethics Board as well as the research ethics boards at the Centre for Addiction and Mental Health and Lakehead University, as required. The recruitment strategies employed are categorized as: (1) recruitment by researchers, (2) recruitment by a third party, and (3) recruitment based on previous participation. For each broad strategy, the specific project approaches are described below and the outcomes are summarized in Table 1.

### Recruitment by Researchers

*Planning study:* All developmental service transfer payment agencies in Ontario were invited in the fall of 2011 to participate in an online survey related to their planning practices. The Executive Directors were initially contacted by the researchers via email, and asked to provide the name and contact information of the staff member in their organization most familiar with their planning practices. These staff were then contacted by email by the researchers and invited to participate in the study; a link to the online survey was provided in the invitation email. While persons with IDD and families were not participants in this study, it is presented here as it formed the basis of the recruitment strategy for identifying planning teams (Study II) – i.e., our recruitment of agencies led to their participation (as a “third party,” see below) in recruiting planning team members.

### Recruitment by a Third Party

*Parent study:* As part of system transformation, the process for applying for developmental services in Ontario is now done through Developmental Services Ontario (DSO) organizations, which are present in nine regions in the province (i.e., Central, Central East, Eastern, Hamilton-Niagara, North East, Northern, South East, South West, and Toronto) (see [www.dson-tario.ca](http://www.dson-tario.ca)). All nine DSO organizations assisted with recruitment in Phase I of the Parent Study (i.e., mail-out survey and telephone interview) by distributing recruitment forms (i.e., a Request for Information form) early on in the application process to parents of adolescents

and adults (age 16 and above) with IDD living at home and seeking services through a DSO between July 4, 2011 and March 31, 2012. Most DSO staff handed out the recruitment forms in person, though three DSOs did so through mass-mailings or mass electronic mailing. Parents interested in participating contacted the researchers directly.

**Planning study:** In the fall of 2011, all developmental service transfer payment agencies in Ontario were invited to participate in an online survey as part of the Planning Study; this survey included a question on interest in participating in future planning-related research. Recruitment for the in-depth interviews of planning teams (Study II) began with contacting those agencies that had expressed interest in future research. Staff from select agencies who had originally participated in the study were emailed and asked whether an adult with IDD receiving support from their organization might be interested in having his/her planning team participate in the study. These staff then approached persons with IDD (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. In order to reflect, as much as possible, the planning reality in the province, the following were considered when selecting agencies: geographic location (i.e., northern, eastern, central, and southwestern Ontario), team composition (e.g., teams with only paid support vs. those with both paid and natural supports), approaches 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).

**Productivity study:** The branch of the MCSS administering the Ontario Disability Support Program (ODSP) mailed information about the Productivity Study (Phase I) and the survey instrument to social benefits recipients residing in the greater Toronto, northern, and eastern regions on July 19, 2012. Completed surveys were mailed directly by participants to the research team.

## Recruitment Based on Previous Participation

**Parent study:** Phases II (i.e., three-month follow-up) and III (i.e., in-depth interviews) of the Parent Study targeted participants from the first phase of the study. Specifically, all Phase I participants were approached to participate in Phase II at the end of the telephone interview with a Parent Study interviewer or by responding to a question added to the bottom of the Phase I mailed out questionnaire. Similarly, a subset of Phase II participants were approached to participate in Phase III of the study. During Phase II, participants were briefly told about Phase III and asked if they might be interested in participating. Only those who answered “yes” were considered for participation in Phase III. For Phase III, the subset of participants in close geographic proximity to the researcher (i.e., within a 3.5 hour drive from Kingston, ON) was identified. In order to include persons with diverse experiences and perspectives, a targeted approach was taken to recruiting from among those who had expressed interest. In particular, we considered parental and adult child ages, geographical locations (e.g., rural, larger city, smaller city), and caring practices and arrangements (e.g., types of services and supports currently in place as well as those being sought through the DSO). In this last phase, the goal was to highlight particular experiences (Booth & Booth, 1998) rather than produce a generalizable sample.

**Productivity study:** The survey completed by ODSP recipients as part of the Productivity Study included a question about interest in participation in further related research. The researchers directly contacted individuals who had indicated willingness to further participate in research to recruit for Phase II of the study (i.e., interviews).

## Results

The different recruitment strategies employed by the various studies (and phases of studies) resulted in different rates of participation, as summarized in Tables 1a to 1c. Participation rates differed greatly not only across studies, but also within studies (i.e., within study phases, or between the study’s sub-studies).

## Recruitment by Researchers

Recruitment by researchers (indicated in Table 1b under who contacted as “MAPS team directly”) was used in only one study.

**Planning study:** In September 2011, all 345 agencies funded by the MCSS were approached to take part in an online survey of agency planning practices as part of the Planning Study. Of these, the 216 agencies that primarily provided services to adults with IDD were eligible to

participate, representing 62.6% of all transfer payment agencies. A member of the research team sent reminder emails every two weeks between September and November 30, 2011, with data collection closing on December 15, 2011. Upon completion of the survey, respondents were entered into a random draw to win one of 15 gift certificates (\$25). Of the 216 eligible agencies, 156 returned a completed survey, yielding a response rate of 72.2% (see Martin, Ashworth, et al., 2012; Martin, Ouellette-Kuntz, et al., 2012).

Table 1a. Summary of Recruitment Efforts and Results Across Studies – Parent Study

Features	Parent Study		
	Phase I	Phase II	Phase III
Design	One-time survey (phone and mail)	Follow-up survey (phone and mail)	Case studies
Participants	Parents	Parents	Parents, adults with IDD, others
Who contacted	DSO	MAPS team after receiving indication of interest	MAPS team after receiving indication of interest
How contacted	Various: handed, mailed or emailed information sheet	Mailed information sheet with self-addressed stamped return envelope	Telephone and/or email
What asked	1 mailed questionnaire (~15 minutes), 1 telephone interview (~30 minutes)	Mailed questionnaire every 6 months (~15 minutes each), telephone interview every 3 months (~15–20 minutes each)	1 to 2 in-person interview with self and others (~2 hours each)
Incentive	\$20	\$50	None
Sample size target	400 parents	200 parents	8 families
Number eligible	1,191 (estimated)	211	112 asked if interested in participating
Number expressing interest	251	n/a	103 of the 112 asked (92%); 12 invited (targeted recruitment)
Number participating	211	181	8
Participation rate	18% of those eligible (211 out of 1,191); 84% of those interested (211 out of 251)	86% of those eligible (181 out of 211)	67% of those invited (8 out of 12)

Table 1b. Summary of Recruitment Efforts and Results Across Studies – Planning Study

Features	Planning Study	
	Study I	Study II
Design	One-time survey (email)	Case studies
Participants	Agencies	Planning team members
Who contacted	MAPS team, directly	Agencies
How contacted	Emailed a letter of invitation to the Executive Directors of all agencies	Various: agency staff spoke with individuals supported and/or family members about the study (note: study information was provided to staff by the MAPS team)
What asked	1 email survey (~30 minutes)	1 in-person interview (~45 minutes each)
Incentive	Draw for one of 15 gift cards (\$25)	None
Sample size target	All 345 transfer payment agencies	8 teams
Number eligible	216 agencies primarily providing services to adults with IDD	Unknown
Number expressing interest	n/a	8
Number participating	156	8
Participation rate	72% of eligible agencies (156 out of 2163)	Not applicable

Table 1c. Summary of Recruitment Efforts and Results Across Studies – Productivity Study

Features	Productivity Study	
	Phase I	Phase II
Design	One-time survey (mail)	One-time survey (interview)
Participants	Adults with IDD or proxy	Adults with IDD
Who contacted	Ministry (ODSP)	MAPS team after receiving indication of interest
How contacted	Mailed survey with self-addressed stamped return envelope	Telephone and/or email
What asked	1 mailed questionnaire (~10 minutes)	1 in-person interview (~60 minutes)
Incentive	None	\$20 gift card
Sample size target	1,200 adults with IDD or proxy	120 adults with IDD
Number eligible	11,709*	2,003
Number expressing interest	n/a	913 of the 2,003 asked (46%); 135 invited (targeted recruitment)
Number participating	2,003	64
Participation rate	17% of those eligible	36.8% of those invited (64 out of 135)

\* While the questionnaire was mailed to 12,000 individuals, 291 were undeliverable (i.e., returned to sender); therefore, participation rates are based on the 11,709 individuals who actually received the questionnaire.

## Recruitment by a Third Party

Recruitment by a third party (indicated in Tables 1a, 1b and 1c under “Who contacted” as DSO, Agencies or Ministry) was used in three studies.

**Parent study:** Between July 4, 2011 and March 31, 2012, staff from each of the nine DSOs distributed 1,191 Request for Information forms to eligible parents seeking services. Parents who were interested in participating contacted the research team directly (using pre-stamped return envelopes or email). Of those who were sent forms, 251 parents returned the Request for Information form to the research team, representing an overall response rate of 21.1%. The response rate varied considerably by DSO region, from 1% to 56%. The 251 responding parents were then sent a Study Information sheet, Consent form, questionnaire, and pre-stamped return envelope; a member of the research team followed up with parents by phone approximately two weeks after the package had been mailed. A total of 221 parents (88.0%) consented to participate; again, response rates varied by DSO region (77% to 100%). Of these 221 parents, 211 (95.5%) provided complete or partial data (209 provided useable surveys and 207 completed telephone interviews).

**Planning study:** As part of the Planning Study, the researchers reviewed the list of organizations that had indicated interest in the agency survey (Study I) in participating in future planning-related research, and sorted organizations based on geographic region and size. A total of ten organizations were contacted beginning in summer 2011, and eight (80%) agreed to take part in the study. Staff at each agency approached an individual (or substitute decision maker) they thought would be interested in participating; all approached agreed to participate. A total of 48 individuals across eight teams were interviewed.

**Productivity study:** The branch of the MCSS administering the ODSP mailed information about the Productivity Study (Phase I) and survey instruments to 12,000 benefit recipients residing in the greater Toronto, northern, and eastern regions on July 19, 2012. Of these, 291 were undeliverable (i.e., returned to sender), meaning that not more than 11,709 received the information package. Of the lat-

ter, 2,003 returned completed surveys, yielding a response rate of 17.1%. Of the returned surveys, only about 30.8% had been completed by the benefit recipients themselves. Surveys had also been completed by a recipient’s parent = (46.5%), care provider (8.8%), sibling (5.9%), or case manager/counsellor (3.1%). A spouse, other family member, trustee/guardian, friend, or “other” had each completed surveys in fewer than 2% of cases. A small proportion (4.1%) of surveys did not include information on who had completed the form.

## Recruitment Based on Previous Participation

Recruitment based on previous participation (indicated in Tables 1a and 1c under “Who contacted” as MAPS team after receiving indication of interest) was used in the remaining three studies.

**Parent study:** Phases II and III of the Parent Study each recruited from participants involved in the previous stage of research. Of the 211 parents who participated in Phase I of the study, 194 (92%) agreed to take part in the follow-up (Phase II), consisting of telephone interviews every three months, and completion of mailed questionnaires every six months for up to two years. In total, 112 parents were told about Phase III. Of these, 103 parents (92%) expressed interest in further participation. A subset of 20 families living within close proximity to the researcher and reflecting diverse participant and care experiences served as the initial Phase III recruitment pool. Throughout the study, members of the research team added families to the recruitment pool as needed in an attempt to capture a diversity of experiences. Four families declined the invitation to participate, and four other families could not be reached by the research team. Recruitment continued until eight families agreed to participate. Participating families were also asked to identify other formal (e.g., paid staff) and informal (e.g., family, friend, neighbour) supports, who had a significant impact on the family’s experience with care and support, and who might be willing to participate. Once identified, either a researcher or the parent contacted the individual to determine their interest in participating. A total of eight formal and four

informal supports were approached, of which six and two agreed to participate. The intent was to also include family members with IDD in interviews. However, only one family member with IDD took part. This participation was limited to a joint interview with his parent.

**Productivity study:** Of those who completed the first phase of the Productivity Study, 913 (45.7%) had indicated their interest in participating in future related research. Of these, 135 were approached to participate, and 64 agreed and were included in Phase II, representing 47.4% of eligible respondents.

## Discussion

The issue of low participation in research is not unique to the field of IDD (for example, in see Blom-Hoffman et al. (2009) in the field of Education). One of the challenges in learning about strategies to improve participation in research lies in the inconsistent reporting of participation rates (Hartage, 2006; Blom-Hoffman et al., 2009; Galea & Tracy, 2007), as well as with the lack of detail about participant recruitment (Cleaver et al., 2010). The current study sought to identify the various participant recruitment strategies used by studies within a larger program of research, as well as the resulting participation rates.

The recruitment methods employed in the MAPS research studies relied on various collaborative approaches to recruiting different target groups, including: distributing information to parents through DSO organizations; mailing information to adults with IDD in receipt of ODSP benefits; asking agencies to identify and pass on information to members of planning teams; and the MAPS team contacting study participants to invite them to extend their involvement into a subsequent phase of the study. It should be noted that planning for each study included determining *a priori* the required number of participants for the proposed analyses. We showed that participation rates across the six MAPS studies varied considerably from slightly below 20% to greater than 90%. The elements of recruitment that may have contributed to exceeding, reaching and not reaching our targets are discussed below.

## Higher Rates of Participation

In general, Table 1 shows that recruitment was most successful when researchers had direct contact with those being recruited. The participants recruited in this way had already expressed an interest in the particular area of research (i.e., Parent Study and Productivity Study). Interviewers noted how passionate participants were about the topic and that respondents particularly welcomed the opportunity to “tell their stories” through interviews rather than simply responding to a mailed survey. Many expressed a belief that participating in research could contribute to change. Researchers conducting studies as part of a larger program of research should consider asking participants about their willingness to be contacted in the future for participation in related studies as part of their overall recruitment strategy.

Related to the issue of who initiates contact with those being recruited is making clear who is conducting the study. The Productivity Study mailed cover letters from both the Ministry and the lead researcher (including her photo). Clearly showing the partnership between researchers and policymakers may have contributed to recruitment success. Similarly, in the Planning Study, agency staff partnered with researchers and approached individuals with IDD and their families about participation. For the Parent Study Phases II and III, the research staff who had previously interviewed parents communicated the request for participation to parents either at the conclusion of an interview or through mail correspondence. This established relationship with a member of the research team appears to have been instrumental in securing high participation in subsequent phases of the project. In the case of Phase III, having parents invite formal and informal caregivers to join the study was not only required, but also highly successful. To maximize participation and participant “buy-in,” research partnerships should be highlighted within the recruitment strategy.

Participation rates were also high in studies in which compensation was offered. It is unclear whether financial compensation or gift cards increase participation though they are clearly welcomed by most participants. The promise of a \$20 gift card for each participant cho-

sen for Phase II of the Productivity Study may have influenced the number indicating interest (45.7%). For researchers with the ability to provide compensation for participants, care must be taken to ensure that the level of compensation offered provides incentive to participate without unduly influencing the decision to participate – especially if the study in question involves risk (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010).

### Lower Rates of Participation

Table 1 also shows that recruitment efforts were least successful when recruiting large samples, particularly when MAPS was unknown to potential participants and the team had to rely on a third party. Our participation rates through third party recruitment for the Parent and Productivity studies are extremely low (17-18%). Such rates require careful consideration of participation bias which we have attempted to address in our reports (Ouellette-Kuntz et al., 2013a; Lysaght et al., 2013). It is important to recognize that, in the absence of a research registry, third party recruitment strategies will continue to play a primary role in IDD research. Researchers dependent on use of a third party for participant recruitment should consider the use of one or more strategies that could lead to higher participation rates – such as highlighting partnerships, providing a “face” for the research team (e.g., through inclusion of a photo on the recruitment letter), and use of appropriate compensation.

We also had lower participation rates in studies that required face-to-face interviews. Some parents who declined the invitation to participate in the Parent Study III expressed concerns related to the time commitment and the more intrusive nature of in-person interviews. Some participants in the Parent Study also expressed disappointment that the research would not contribute to tangible changes in their lives or that of family members. The coordination of face-to-face interviews also complicates participation, as it requires having several dedicated staff available to fit into participants’ schedules. While our experience is limited, we did observe that while most parents wanted to share photos of their sons or daughters or have us meet

them so we would “know who we were talking about,” most parents were not enthusiastic about facilitating direct participation of their children in research, citing scheduling or time constraints, and communication difficulties. Face-to-face interviews also sometimes limited participation to those who were in reasonable proximity, thereby reducing the potential participant pool. The extent to which telephone interviews or other means of data collection could replace the need for face-to-face interviews should be considered, especially when a large sample size is desired.

While recruitment based on previous participation led to high rates in the Parent and Productivity studies, the time lag between the expression of interest and research participation may have negatively impacted participation. For example, the longer the lag, the more likely it becomes that individuals will not recall having volunteered to take part in future research, no longer remember the study, or have changes in commitment which preclude their involvement. In addition, a lag also meant that email addresses and telephone numbers provided were not always valid when researchers attempted to follow-up.

Finally, while partnering with policymakers strengthened our research program in many ways, it was difficult for some participants to separate the research team from the Ministry; some may have believed that the researchers worked *for* the Ministry, rather than *with* the Ministry and some may have been distrustful of statements that information shared as part of the study would not affect services or entitlements. For example, some adults with IDD indicated concerns that information they shared with researchers regarding their productivity might place their disability pension in jeopardy.

### Partnering

Developing and managing strong partnerships is critical for effective recruitment. However, partnering requires a significant investment of time and resources. Partnerships may need to be extensive, including multiple levels of involvement (individuals with IDD, family members, agencies, policymakers) and many different groups within a given level (for example to ensure geographic representation or

access to a sufficiently large pool of potential participants). However, the more individuals and groups are involved, the greater the risk of a breakdown in communication will be. The control of various aspects of the research need negotiating and renegotiating to ensure buy-in and access to potential research participants.

Partnering presents opportunities for learning from each other resulting in more effective knowledge mobilization. Partnering is particularly important in IDD research as recruitment relies extensively on third parties. Hilgenkamp et al. (2011) reported on a very successful third party recruitment strategy whereby they recruited 1050 adults with IDD 50 years of age or older across three health care organizations in the Netherlands (49.7% consent/invited rate). They stated “[I]nvolvement of top and middle management in the entire process and a thorough communication plan (with a focus on key groups such as professional caregivers) proved of paramount importance to effectively organize this kind of large-scale research projects” (p. 1103).

Through the MAPS program, we attempted to create mutual trust and teamwork with various stakeholders: individuals with IDD, parents, service providers, DSO workers, and the Policy Research and Analysis Branch of MCSS. We met regularly with stakeholder groups, we made extensive use of our accessible website, and we offered continued opportunities to contribute to research to those who indicated an interest. It is clear that while the partnered approach has been beneficial, there is still a lot to be done.

## Conclusion

There is a need to more fully engage individuals with IDD and their parents in research aimed at system improvement. Partnering with persons with IDD and families in research to enhance supports available to persons with IDD is not only desirable but necessary. Often, studies that aren’t based on large sample sizes are dismissed as non-representative, though carefully crafted recruitment strategies of small numbers may yield important findings. Beyond reaching sample size targets and ensuring representation, researchers must consider both the logistics and outcomes associated with various recruitment strategies. In particular, we have found that partnering in research – with per-

sons with IDD, their families, service providers, and the government office overseeing services has increased not only the participation of persons with IDD in our research, but also the relevance of the research itself. The partnerships we were a part of, though they consumed significant time and resources, also allowed us to conduct research that might not have been possible otherwise.

In an era of scarce resources, we need to increase collaboration and rely on partnerships. By presenting the recruitment approaches, results and analyses of three distinct projects relying on extensive partnerships, we hope to contribute to knowledge of best practices in recruitment in IDD research. Such knowledge may encourage researchers in Ontario to continue to work with stakeholders to develop a positive environment for recruitment, and may ultimately contribute to the quality and relevance of research in this arena.

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The views expressed in this article are not necessarily the views of all MAPS partners, researchers, collaborators or those of the Ministry.

## Key Messages From This Article

**Persons with disabilities:** Researchers want to make sure that you are included in the research about your supports and services. We think that partnering with you, your family, service providers, and the government will help us do better work.

**Professionals:** Partnerships between service providers, government, and researchers can lead to an increase in the participation of persons with IDD in research, and therefore to research that is more meaningful to the people who will benefit from it.

**Policymakers:** Partnerships in research – with persons with IDD, families, service providers, and policymakers is – important to increasing the success and relevance of studies.

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