

Citizen Engagement – the Case of Parents of Adults with Intellectual and Developmental Disabilities (IDD) in Ontario

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INTRODUCTION

- **Citizen engagement** is the meaningful involvement of citizens in policy or program development and evaluation, and is key to civil society. This engagement is done to ensure that all, including vulnerable populations, are heard and can contribute to public policy decisions (Phillips & Orsini, 2002).
- Recent events in Ontario provide an opportunity to examine different forms of citizen engagement in a common context: social policy concerning services and supports for adults with IDD. The history of society’s responses to the needs of persons with IDD has been heavily influenced by **parents**. Their advocacy played a role in the creation of over 300 community-based agencies that provide services to adults with IDD, and in the closure of institutions (1987 to 2009).
- A significant outcome of recent system transformation in Ontario has been the adoption of the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act (SIPDDA, 2008; enacted in 2011)*. One of the most visible and contentious changes brought about by the new legislation was the creation of **Developmental Services Ontario (DSO)** organizations offering a standard process for accessing services for adults with IDD across the province.
- In 2010, the Ministry of Community and Social Services invested in the **MAPS study** of parents accessing services for their adult children with IDD through the newly created DSOs. Study findings indicated that after 24 months, many - including those in or near crisis - continued to wait for services (Ouellette-Kuntz *et al.* 2014).
- As the MAPS project was being conducted, a dramatic increase in complaints from parents was noted by the provincial **Ombudsman** who announced an investigation into the developmental services system (Ombudsman Ontario, 2012). The unprecedented increase in complaints and media attention led to the creation of the **Ontario Legislative Assembly’s Select Committee on Developmental Services** in October 2013. This committee heard from more than 140 presenters at 14 public hearings and received over 300 written submissions; the final report was released in August 2014.

OBJECTIVE

This project aims to develop knowledge and actions regarding citizen engagement in the developmental services sector in Ontario by examining how parents engaged in the above activities. This poster focusses on the analysis of the Select Committee hearings.

METHODS

Document analysis was undertaken to evaluate the engagement of parents. Publicly available transcripts from the Select Committee hearings were analyzed independently by 3 researchers using a framework approach (familiarization, identification of thematic framework, coding, organization of the index, mapping and interpretation; Pope *et al.*, 2000). Rowe *et al.*’s (2008) nine criteria for effective citizen engagement framework (see Table 1) guided the coding.

Table 1. Framework guiding coding

Acceptance Criteria	Process Criteria
Consider whether an engagement activity and outcome would be perceived as fair by the participants.	Consider whether an engagement activity was effectively planned and implemented.
Representativeness	Resource Availability
Independence	Task Definition
Early Involvement	Structured Decision-Making
Influence	Cost-effectiveness
Transparency	

RESULTS

COMMON THEMES

	ACCEPTANCE	PROCESS
	Representativeness The transcripts indicate that parents represented their adult children who... <ul style="list-style-type: none"> • live in a variety of settings including with them, in a group home, on their own including in separate living space in their family’s home, in a hospital or a nursing home, and • have a variety of conditions leading to their need for services including autism spectrum disorder, dual diagnosis, Down syndrome, cerebral palsy, seizure disorders and a variety of less common syndromes. Parents who participated... <ul style="list-style-type: none"> • were mostly mothers. • represented families who were currently in crisis, had previously experienced a crisis, as well as some not reporting crisis. • talked about issues of quality related to the formal services and supports they received and the impact of unpaid supports; some noted supports they were requesting/waiting for. 	Structured Decision- Making The transcripts indicate that Select Committee members at times asked specific questions ; for example: “ <i>what is the school board doing around FASD?</i> ” and “ <i>what are your thoughts on the DSO?</i> ” thereby attempting to guide the process .
	Independence The transcripts often included reference to parents having other roles (e.g. agency directors or board members) and sometimes revealed personal connections between parents and members of the Select Committee suggesting the potential for presentation bias. One parent commented: <i>“I’m the chair of Community Living [...]’s advocacy committee, and I’m a member of the [...] board of directors. I’m also the parent of [...], who was born with Down syndrome. He is in the room today.”</i>	Resource Availability A small number of parents and the Chair acknowledged the time constraints faced by the Committee (number of minutes per speaker, number of hours per day).
	Influence While the documents do not provide clear evidence of influence, parents made recommendations to the Select Committee about things such as increasing funding, increasing housing options, reducing medication use, and the need for specialized diagnostic clinics (e.g. for Fetal Alcohol Spectrum Disorder).	
		Transparency The hearings were held in open forum and transcribed verbatim; however parents did not comment on the procedures or criteria for participation or how they understood their input would be used. One parent commented: <i>“...there would not be a Select Committee if there wasn’t a political commitment to change – that the status quo is not good enough...”</i>

ISSUES RAISED

Inadequate Funding: “There’s no money to provide to people, for Special Services at Home and Passport funding in particular.”

Lack of Compassion: “Occasionally, we see rays of light; we see some politicians who care. I wish all of them cared. They don’t understand the struggle we go through, and this is not just with autism, but it’s with other developmental delays. It’s very, very sad, and it’s mainly shame and blame the parents. We have to go begging for what the kids need, and it’s more shame and blame, calling our kids bad names.”

Unresponsive System: “I have a letter here, which we received from DSO yesterday. She has been on a residential wait-list now for over 10 years, and we just got this saying that if we are still looking for a residential placement, please contact the appropriate person because there is a new application process. So that’s what families get to deal with.”

Transition to Adult Services: “Okay, I think you all know that children are allowed to attend school until they’re 21, and I think that’s when the crisis begins to happen, when families begin to fall into crisis.”

KEY MESSAGES

Six of the nine criteria for effective citizen engagement were identified through review of the transcripts.

ACCEPTANCE	PROCESS
<ul style="list-style-type: none"> • Documentation of whose voice is represented was most evident. Diverse experiences were represented in terms of the adult children’s living arrangement and diagnoses and the families’ supports and coping. However, the transcripts do not provide the information required to assess the representativeness of the parents and issues with regards to other factors such as geographic distribution (urban/rural) or ethno-cultural identity. • The transcript analysis suggests the hearings could be perceived as biased due to a lack of independence. • That parents felt they could make direct recommendations to the Committee suggests they perceived they had influence. However, demonstration of influence takes time. We will examine the Committee’s report and the Ministry’s response to determine the extent to which parents’ recommendations are featured. • As the transcripts did not discuss the planning involved or the intent of the activity, they do not provide much evidence of early involvement or transparency. 	<ul style="list-style-type: none"> • Documents reveal limited attempts at structured decision-making and identify resource limitations. There was no evidence of attention to the cost-effectiveness of the activity or clarification of the Committee’s task.
<p>Conclusion: The document analysis suggests that the effectiveness of the engagement activity may have been compromised due to potential presentation bias and insufficient time to allow all interested parents to engage adequately with the Select Committee. In their work, Rowe <i>et al.</i> (2008) have noted that public hearings such as the Select Committee activity generally score low to moderate on acceptance criteria and low on all process criteria.</p>	

NEXT STEPS

Future steps for this project include examining the Select Committee’s Report, and the Ministry of Community and Social Services’ response.

Additionally, results will be contrasted with other concurrent engagement activities, such as the MAPS Parent Study and the Ombudsman’s investigation.