

**Knowledge Mobilization in Community-Based Services: Supporting Friendships for Adults
with Intellectual Disabilities**

Casey Fulford

Thesis submitted to the University of Ottawa
in partial fulfillment of the requirements for the
Doctor of Philosophy in Clinical Psychology.

School of Psychology

Faculty of Social Sciences

University of Ottawa

© Casey Fulford, Ottawa, Canada, 2020

Acknowledgements

I am extremely grateful to all the people who have supported me to complete my dissertation and Ph.D. in Clinical Psychology. Dr. Virginie Cobigo, my dissertation supervisor, has played an instrumental role in my development as a researcher and in my knowledge of and perspectives regarding support for individuals with disabilities. She has provided invaluable guidance and encouragement throughout every step of my dissertation. Dr. Cobigo is an incredibly dedicated supervisor and I feel very privileged to have been mentored by her over the past six years. I am also appreciative of the Informed Decisions and Actions for Inclusion research team for fostering a collaborative and supportive work environment. I am thankful to the volunteers who supported my research, including Madelaine Ressel, Joyce Younes, Vivian Ta, and Alia Hafez. They were a pleasure to work with and facilitated my data collection and data analysis, making the dissertation process go efficiently and smoothly. I am also very appreciative of the time Patrick Labelle spent providing instruction on systematic literature reviews and qualitative data analysis.

I would like to express my gratitude to my committee members, Drs. Louise Lemyre, John Sylvestre, and Jean- François Bureau for providing insightful feedback that strengthened my dissertation. They provided feedback on my dissertation proposal, after I completed the research activities outlined in Chapter 4, and at the pre-read stage of this dissertation. Their comments vastly contributed to the development of literature review, research methods, and implications.

I sincerely appreciate all the time and effort provided by the community-based organization with whom we partnered to evaluate knowledge mobilization activities. I would like

to thank the director of the organization and the advisory team staff members for their contributions to my research. I am also very grateful to the caregivers and service-users who shared their experiences and knowledge with me. I appreciate the support provided by the Multidimensional Assessment of Providers and Systems (MAPS) research team, including Drs. H  l  ne Ouellette-Kuntz, Lynn Martin, Rosemary Lysaght, and my supervisor, Dr. Cobigo. They facilitated my data collection by distributing recruitment material through the MAPS network. I am also grateful to Patricia Lamarche at Valor & Solutions for distributing recruitment material to their networks, as well as organizing and hosting our online workshops. I would also like to thank the service-providers that answered my questionnaires and participated in interviews regarding knowledge sharing activities. All of the above mentioned people were integral to the successful completion of my dissertation.

In addition to the incredible team that supported the development of my dissertation, I would like to thank the other people who provided integral guidance during my graduate training. I am tremendously grateful to Dr. Yolanda Korneluk for the instrumental clinical supervision and mentorship she provided to foster my professional development. I am honoured to have been a member of her team and am very grateful for the clinical opportunities she provided me with. Finally, I would like to thank all of my family and friends who supported me throughout this process. I am sincerely appreciative of my friend and colleague, Danielle Petricone-Westwood, my partner, Doron Feldman, and my mother, Patricia Rockman, who have provided unwavering emotional support and encouragement. I am incredibly grateful to have them in my support network as I continue the journey toward becoming a clinical psychologist. My graduate research was financially supported by Ontario Graduate Scholarship (2016-2018

and 2019-2020) from the Government of Ontario Ministry of Training, Colleges and Universities, and the Social Sciences and Humanities Research Council (2018-2019).

Table of Contents

Abstract.....	ix
SECTION 1: Knowledge Mobilization for Community-Based Social Issues.....	1
Chapter 1: General Introduction	2
Knowledge into Policy and Practice	4
The Canadian Context: Terms and Conceptualizations.....	5
Knowledge Translation	5
Integrated Knowledge Translation.....	7
Knowledge Mobilization	9
Implementation Science: Understanding how to Move Knowledge into Practice	10
Conceptual Models and Theories of Implementation	11
Evaluation of Conceptual Models.....	15
Knowledge Mobilization in Community-Based Organizations.....	18
Factors that influence knowledge mobilization	19
The Case of Friendship Support for Adults with Intellectual Disabilities.....	28
Research Objective and Questions.....	33
SECTION 2: Fostering Friendships for Individuals with Intellectual Disabilities	35
Chapter 2: Friendships and Intimate Relationships among People with Intellectual Disabilities: A Thematic Synthesis	36
Contribution	37
Preamble	38
Abstract	40
Introduction.....	41
Materials and Methods.....	43
Results.....	46
Discussion	65
References.....	75
Chapter 3: A Review of Strategies to Support Friendships for Adults with Intellectual Disabilities.....	86
Contribution	87
Preamble	88
Abstract	90
Introduction.....	91
Method	92

Findings.....	96
Conclusion	105
SECTION 3: Assessing a Knowledge Mobilization Process in Community-Based Social Settings to Foster Friendships for Individuals with Intellectual Disabilities	108
Chapter 4: A Process Evaluation of Knowledge Mobilization in Community-Based Services: A Case of Friendship Support for Adults with Intellectual Disabilities.....	109
Contribution	110
Preamble	111
Abstract	112
Introduction.....	113
Method	115
Findings.....	121
Discussion	134
Chapter 5: Service-Provider Perspectives on Knowledge Mobilization Methods in Community-Based Services Supporting Adults with Intellectual Disabilities: Post-Test Surveys and Interviews.....	141
Contribution	142
Preamble	143
Abstract	144
Introduction.....	145
Method	146
Findings.....	154
Discussion	161
SECTION 4: Discussion	168
Chapter 6: General Discussion	169
Overview of Dissertation	170
Lesson 1: Overcoming Challenges Associated with a Paucity of High-Quality Research.....	171
Lesson 2: Adapting Knowledge Mobilization Practices to Community-Based Settings	176
Lesson 3: The Importance of Communication Methods and Content	177
Lesson 4: A Note about Use of Language	180
Limitations	180
Future Directions	182
Conclusion	184
References	186

Appendix A: Chapter 2 Figures Explaining Search Process and Reasons for Article Exclusion.....	222
Appendix B: Mixed Methods Appraisal Tool (MMAT).....	225
Appendix C: Focus Group Protocol for Service-Users and Family Caregivers	226
Appendix D: De-identified Evidence Brief	230
Appendix E: Interview Protocol for Interview with Director of Organization	251
Appendix F: Conference Workshop Material.....	253
Appendix G: Links to Online Modules	265
Appendix H.1: French Online Workshop Slides.....	266
Appendix H.2: English Online Workshop Slides	281
Appendix I.1 : French Website Questionnaire.....	296
Appendix I.2 French Workshop Questionnaire.....	301
Appendix I.3: English Website Questionnaire	306
Appendix I.4: English Workshop Questionnaire.....	311
Appendix J: Interview Protocol with Service-Providers.....	316

List of Tables and Figures

Chapter 1: General Introduction

Figure 1.1: The Grol and Wensing Implementation of Change Model.....	14
--	----

Chapter 2: Friendships and Intimate Relationships among People with Intellectual Disabilities: A Thematic Synthesis

Table 2.1: Characteristics of Selected Studies.....	47
Table 2.2: Quality Assessment of Selected Studies.....	53
Table 2.3: Structure of Themes, Example Quotes, and Number of Studies Contributing to Each Theme.....	54

Chapter 3: A Review of Strategies to Support Friendships for Adults with Intellectual Disabilities

Figure 3.1: Systematic online database literature search findings and reasons for article exclusion.....	97
Figure 3.2: Hand search findings and reasons for article exclusion.....	97
Table 3.1: Quality Assessment of Included Studies.....	98
Table 3.2: Characteristics of Selected Studies.....	100

Chapter 4: Testing a Knowledge Mobilization Process in Community-Based Services: A Case of Friendship Support for Adults with Intellectual Disabilities

Figure 4.1: Summary of the Grol and Wensing Implementation of Change Model and intended research activities.....	115
Figure 4.2: Summary of the Grol and Wensing Implementation of Change Model and actual research activities.....	130

Chapter 5: Service-Provider Perspectives on Knowledge Sharing Methods and Content Regarding Friendship Support for Adults with Intellectual Disabilities in Community-Based Services: Pre-Test Knowledge Mobilization Surveys and Interviews.

Table 5.1: Participant Numbers across Distribution Formats for both Phases.....	151
Table 5.2: Participant Demographics.....	151
Table 5.3: Breakdown of Phase 2 (Interview) Participant Demographics Intervention Methods.....	152
Figure 5.1: Service-provider responses to the statement "The content could be used to adapt practices", categorized by recruitment method.....	154
Figure 5.2: Service-provider responses to the statement "The content included new information regarding support strategies", categorized by recruitment method.....	154
Figure 5.3: Service-provider responses to the statement "The format was clear and easy to understand", categorized by recruitment method.....	157
Figure 5.4: Service-provider responses to the statement "What would be the most useful format for distributing the content?" categorized by recruitment method.....	157

Abstract

The objective of this dissertation was to conduct an evaluation of a knowledge mobilization process in a community-based organization that supports adults with intellectual disabilities. The aim of the project was to understand how stakeholders share knowledge, use knowledge, and collaborate to make decisions regarding practices to support friendships for adults with intellectual disabilities. We produced two literature reviews; one systematically documented the views of adults with intellectual disabilities with regard to their relationships, and the other examined existing literature on strategies to support friendships. We also conducted two primary research studies in which we documented and evaluated knowledge mobilization activities in community-based organizations. We used a mixed-methods approach and collected data from a variety of stakeholder groups associated with a community-based organization, including staff members and the organization's director, adults with intellectual disabilities, and family caregivers. Additionally, we collected data from staff working in a variety of community-based organizations that support adults with intellectual disabilities. During our primary research studies, we produced a variety of knowledge mobilization outputs regarding friendship support, including an evidence brief, a conference presentation, online presentations in French and English, and an informational website in French and English. The results of the studies included in this dissertation, our recommendations regarding community-based knowledge mobilization, and the knowledge mobilization outputs we developed can be used to improve knowledge mobilization practices in community-based services. Studying knowledge mobilization to support individuals with intellectual disabilities highlights some of the complexities that should be considered within

community-based services, such as working with a variety of stakeholder groups, and including stakeholders that are potentially vulnerable to social exclusion.

SECTION 1: Knowledge Mobilization for Community-Based Social Issues

Chapter 1: General Introduction

Existing evidence and knowledge should be used to inform policy and practice to maximize the effectiveness of services (Graham, Tetroe, and KT theories group, 2007). Research on moving knowledge into practice has predominately been conducted in medical and clinical services, compared to more complex community-based social services (Hardwick, 2017). In this dissertation, we sought to understand a specific case within community-based social services. Specifically, we focused on how knowledge on supporting friendships for adults with intellectual disabilities is shared in community-based organizations. The objective of this dissertation was to conduct an evaluation of a knowledge mobilization process in a community-based organization that supports individuals with intellectual disabilities. The aim of the project was to understand how stakeholders share knowledge, use knowledge, and collaborate to make decisions regarding practices.

This dissertation consists of four sections. Section 1 [the current section], includes a conceptual discussion of the principles for using knowledge to inform practice. Section 2 [Chapters 2 and 3] contains a substantive review of the current context of friendships of adults with intellectual disabilities. Specifically, Chapter 2 is a systematic literature review on the perspectives of adults with ID regarding their relationships, and Chapter 3 is a systematic literature review on strategies for supporting friendships for individuals with ID. Section 3 [Chapters 4 and 5] includes findings from evaluations of knowledge mobilization activities within community-based services. Specifically, Chapter 4 presents a natural field experiment, and Chapter 5 examines knowledge sharing activities with service-providers. Section 4 [chapter 6] is a general discussion.

Knowledge into Policy and Practice

Although many topics are studied across a variety of fields, simply presenting research findings in scientific journals and at conferences is not sufficient to affect change in policy and practice (Levin, 2008; Sharon E. Straus, Tetroe, & Graham, 2011). If scientific evidence is not incorporated into policy and practice, it will not affect change in population outcomes (Colditz & Emmons, 2017; Graham et al., 2006); individuals (e.g., patients, clients, service-users) will not receive services that are proven to be beneficial, and ineffective services may continue to be implemented (Graham, Tetroe, & KT Theories Research Group, 2007). Moving research knowledge into practice provides “society the full return on our collective investment in research” (Colditz & Emmons, 2017, p. 2). Researchers must work with a variety of stakeholders and actively engage in activities to facilitate the uptake of research knowledge by non-researchers. The way in which we try to move knowledge into policy and practice is impacted by how we conceptualize this process.

There are a myriad of terms used to describe the process (or steps in the process) of using scientific research findings to inform policies and practices (Graham et al., 2007; Graham et al., 2006; Levin, 2008; Rabin & Brownson, 2017; Straus et al., 2009). Terms include knowledge translation, knowledge mobilization, knowledge to action, knowledge exchange, knowledge cycle, and knowledge transfer, among a variety of others (Graham et al., 2006; Grol, Wensing, Bosch, Hulscher, & Eccles, 2013; Levin, 2008; Straus et al., 2009; Straus et al., 2011; Worton, Loomis, Pancer, Nelson, & Peters, 2017). These terms are frequently used interchangeably, and definitions are inconsistent and not always operational (Graham et al., 2006; Rabin & Brownson, 2017; Tetroe et al., 2008). This can be problematic, as different terms are based on varying

underlying assumptions (Bowen & Graham, 2013), which inhibits consensus and mutual understanding amongst researchers (Ward, 2017).

The Canadian Context: Terms and Conceptualizations

Within Canada, the primary terms and conceptualizations used have been influenced by the federal government research funding bodies, Social Sciences and Humanities Research Council (SSHRC) and Canadian Institutes of Health Research (CIHR) (Bennet et al., 2007; Naidorf, 2014). Within the health sciences, the primary terms that are currently used are knowledge translation and integrated knowledge translation (Government of Canada, 2015). The most common term within the social sciences is knowledge mobilization (Naidorf, 2014). A growing body of literature has been used to inform these definitions and to better understand the different ways in which knowledge can be moved into practice. It is important to note that authors differ in their conceptualizations of these terms and that the below explanations highlight the predominant viewpoints of Canadian researchers and federal funding bodies. Given the broad terminology related to using knowledge to inform practice, we do not attempt to cover the exhaustive list of terms used by different authors. Rather, we intend to provide a more nuanced understanding of the common terms used within Canada.

Knowledge Translation

Within Canada, the term knowledge transfer was used within the medical sector to describe a process through which research was conducted by scientists and the results were provided to individuals that would use the findings (Schryer-Roy, 2005). However, the unidirectional or push nature of knowledge transfer was criticized because it did not facilitate the use of these findings in decision making (Schryer-Roy, 2005). Overtime, there was a general

trend toward using the term knowledge translation, which is a definition that has transformed over the years to include more interactive processes. The current conceptualization of knowledge translation entails educating stakeholders on the findings of scientific research on a relevant topic, and assisting them to use these findings in practice (Government of Canada, 2015). Specifically, CIHR defines knowledge translation as "a dynamic and iterative process that includes synthesis, dissemination, exchange and ethically sound application of knowledge to improve the health of Canadians, provide more effective health services and products and strengthen the health care system" (Government of Canada, 2015, Introduction section, para. 4).

It is important to understand the different components included in the above definition of knowledge translation. Knowledge synthesis involves researchers gaining an understanding of the current state of scientific findings in a particular area, and then synthesizing and critiquing this information (Straus & Leung, 2010). For example, knowledge could be obtained from primary research articles and synthesized into a systematic review (Government of Canada, 2010a). Knowledge dissemination consists of actively tailoring and communicating findings to knowledge users in an accessible format (Government of Canada, 2010; Government of Canada, 2015; Graham et al., 2006; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). Knowledge users are individuals who can use research knowledge, and can include policy and decision makers, service-providers, clinicians and the general public, among others (Government of Canada, 2005; Graham & Tetroe, 2009). An example of how knowledge could be disseminated to one group of knowledge users is to distribute practice guidelines to practitioners. It is worth noting that despite the CIHR definition of knowledge translation highlighting the exchange of knowledge amongst all stakeholders, non-academic stakeholders are referred to as knowledge users (Abma et al., 2017). Therefore, knowledge users continue to be defined as those who use knowledge derived

from research, which separates them from researchers and does not infer that they may also contribute knowledge (Abma et al., 2017). The definition of knowledge users suggests that conceptualizations of knowledge translation view knowledge as flowing in one direction, from researchers to knowledge users.

Conceptualizations of knowledge translation tend to assume that research knowledge is developed by researchers at universities and then delivered in an accessible manner to non-academic knowledge users (Greenhalgh, Jackson, Shaw, & Janamian, 2016). The focus of knowledge translation is on identifying gaps in knowledge and providing targeted interventions to fill knowledge users' knowledge gaps (Government of Canada, 2010b). Within the biomedical field, knowledge translation is typically based on the view that researchers are the experts who share their knowledge with relevant stakeholders, and research findings can then be applied across contexts (Bowen & Graham, 2013) to increase conceptual knowledge and change knowledge users' practices (Government of Canada, 2010b).

Integrated Knowledge Translation

Researchers have stated that “the knowledge translation movement is moving towards integrated knowledge translation” (Manojlovich, Squires, Davies, & Graham, 2015, p. 8). Integrated knowledge translation consists of a collaborative process in which researchers and knowledge users work together throughout all stages of the research process to help facilitate the relevance of research findings within the settings that they will be used (Kothari, McCutcheon, & Graham, 2017; Kothari & Wathen, 2013). This approach recognizes that while researchers provide methodological research skills, other stakeholders have crucial information on the topic of focus and the setting where knowledge translation is occurring (Kothari et al., 2017).

Integrated knowledge translation is a term commonly referred to within the medical sciences (Gagliardi, Berta, Kothari, Boyko, & Urquhart, 2016; Kothari et al., 2017). It is similar to research approaches such as participatory action and collaborative research (Straus, Tetroe, & Graham, 2013). Indeed, the integrated knowledge translation approach has been heavily informed by participatory research methods (Government of Canada, 2012).

The primary difference between traditional knowledge translation (also referred to as end-of-grant knowledge translation) and integrated knowledge translation is that integrated knowledge translation engages knowledge users throughout the entire research project (McGrath, Lingley-Pottie, Emberly, Thurston, & McLean, 2009). This allows knowledge users to contribute to the development of research questions, methods, and data analysis; contribute to the interpretation of results; and engage in dissemination and implementation activities (Government of Canada, 2015; Lapaige, 2010). Compared to end-of-grant knowledge translation, integrated knowledge translation aims to provide more contextually relevant research questions and applicable findings, as well as promote co-learning between researchers and knowledge users (McGrath et al., 2009; Sharon E. Straus, Tetroe, & Graham, 2013). Conceptualizations of integrated knowledge translation recognize that researchers and knowledge users contribute different knowledge and skills, and collaboration amongst stakeholders throughout the research process facilitates change in practices (Government of Canada, 2012; Kothari et al., 2017). Knowledge mobilization, a term commonly used within the social sciences, similarly highlights the integral contributions of knowledge users.

Knowledge Mobilization

Within the social sciences, there tends to be greater acknowledgement that non-research knowledge is also important for adapting findings to the local context (Bennet et al., 2007; Bowen & Graham, 2013). The conceptualization of knowledge mobilization highlights the reciprocal exchange of knowledge amongst stakeholders (Government of Canada, 2012). However, with the advent of integrated knowledge translation, a shift appears to be occurring within the medical field as well. Both integrated knowledge translation and knowledge mobilization view researchers and different stakeholder groups as important contributors of knowledge. For example, with regard to knowledge mobilization, Bennet and colleagues (2007) state, “It combines knowledge gained from research, the accumulated knowledge and experience of researchers, the specialty knowledge of change agents and organizational or community development specialists, and the knowledge acquired from the lived experience of community leaders and citizens” (p. 13).

While definitions of integrated knowledge translation emphasize that knowledge users and researchers work together throughout all stages of the research process, definitions of knowledge mobilization tend to be more vague with regard to how stakeholders collaborate and contribute their knowledge, and the level of involvement appears to vary widely across definitions (e.g., Activating Change Together for Community Food Security: Knowledge Mobilization Working Group., 2014). Despite this variability, conceptualizations of knowledge mobilization consistently highlight the importance of social interactions to create knowledge and indicate that knowledge mobilization aims to support the co-creation of knowledge amongst stakeholders (Abma et al., 2017; Bowen & Graham, 2013; SSHRC, Government of Canada,

2012). Knowledge mobilization is a highly social process that is influenced by stakeholders' viewpoints, experiences, abilities, and limitations (Bennet et al., 2007). When comparing the definitions that are primarily used within Canada for describing the movement of knowledge into practice, knowledge mobilization appears to most heavily emphasize the impact of social interactions amongst stakeholders.

Knowledge mobilization differs significantly from definitions commonly used within the health sciences in that knowledge mobilization does not emphasize implementing change as the primary goal. Rather, it highlights the importance of knowledge sharing and co-creation of knowledge amongst stakeholders, which “may benefit users and create positive impacts within Canada and/or internationally, and, ultimately, has the potential to enhance the profile, reach and impact of social sciences and humanities research” (Government of Canada, 2018, Knowledge Mobilization section, para. 1). Knowledge can be used in a variety of ways, including changing individual's perspectives, influencing decisions, or affecting changes in practice (Worton et al., 2017). While conceptualizations of knowledge translation within the medical sector tends to focus on outcomes of implementing specific interventions or policies, knowledge mobilization within the social sector tends to highlight the social nature of this process and places greater emphasis on knowledge sharing activities and also on how this process can impact the numerous and varying stakeholders involved.

Implementation Science: Understanding how to Move Knowledge into Practice

As indicated above, scientists are interested in how to move knowledge into practice. Although an increasing focus of academia is on implementation (i.e., using research knowledge to change or adapt practices), the specific methods regarding how to do this have not yet been

explored in depth (Colditz & Emmons, 2017). The purpose of implementation science (or implementation research) is to enhance our understanding of how to move research knowledge into real-world practices (Bauer, Damschroder, Hagedorn, Smith, & Kilbourne, 2015). Essentially, implementation science is the study of knowledge mobilization and knowledge translation activities and their effectiveness in changing practices.

Implementation research stemmed from the awareness that efficacious services and programs developed or evaluated through research often do not impact the practices of clinicians and community service-providers (Dearing, Kee, & Peng, 2017). Although implementation science previously focused on describing the facilitators and barriers to implementation, there has been a shift toward evaluating implementation activities to determine their effectiveness (Bauer et al., 2015). According to Ogden and Fixen (2014), central questions in implementation science are “What shall be implemented, how will the task be carried out, and who shall do the work of implementation?” (p. 4). Implementation research also examines how to adapt knowledge to the local context, as it is important to find a balance between the fidelity of an intervention and adapting an intervention to meet the needs of and constraints of the local setting (Ogden & Fixsen, 2014). Due to the complexity involved in changing practices, it is recognized that efforts to use knowledge to implement change should be informed by conceptual models and theories (Nilsen, 2015; Rabin & Brownson, 2017; The Improved Clinical Effectiveness through Behavioural Research Group, 2006).

Conceptual Models and Theories of Implementation

A multitude of theoretical models have been developed regarding how to effectively incorporate research knowledge into changes in practice (Estabrooks, Thompson, Lovely, &

Hofmeyer, 2006; Grol, Wensing, Bosch, Hulshar, & Eccles, 2013). Conceptual models can provide structure and justification for implementation activities, help organize thinking, support observation, and assist with analysis (Graham & Tetroe, 2009). This can facilitate understanding of how change occurs and why different implementation interventions vary in effectiveness (Graham et al., 2007; Tabak et al., 2017). Furthermore, engaging in activities informed by a given model offers an opportunity to provide empirical data regarding that model (Tabak et al., 2017).

Planned change and process models and frameworks offer practical guidance for engaging in implementation of change (Graham et al., 2007; Nilsen, 2015). These models clarify key components required for successful implementation, and they typically outline a series of steps to follow in order to effectively implement change (Nilsen, 2015). In a systematic review conducted by Graham and colleagues (2007), common steps were identified across 31 different theoretical models of planned actions, which were developed by researchers across a variety of disciplines. Ultimately, Graham and colleagues (2007) determined 10 common steps of planned action models:

1. Identify a problem that needs addressing
2. Review the evidence or the literature
3. Adapt the evidence and/or develop the innovation
4. Assess barriers to using the knowledge
5. Select and tailor interventions to promote the use of the knowledge
6. Implement the innovation
7. Develop a plan to evaluate use of the knowledge

8. Evaluate the outcomes or impact of the innovation
9. Maintain change - Sustain ongoing knowledge use
10. Disseminate results of the implementation process (p. 939).

Grol and colleagues (2013) published a chapter reviewing process theories of implementation of change. Process theories include content regarding how to plan, organize and schedule activities, as well as how knowledge users will use and be affected by the activities (Rossi, Lipsey, & Freeman, 2003). Grol and Wensing (2013) identified common features of implementation process theories and developed a model that included these elements. The steps of the Grol and Wensing (2013) model align with the common steps of planned action models identified by Graham and colleagues (2007). Although the model is based on the summary and evaluation of existing process models, Grol and Wensing (2013) noted that the scientific basis underlying their model still needs to be examined, as models describing how to move research into practice are rarely systematically evaluated. Despite the fact that many models used in implementation research are vague regarding how to share and implement knowledge (Tabak et al., 2017; Ward, 2017), a practical and comprehensive guide regarding details for each step of the Grol and Wensing Implementation of Change Model was developed based on existing implementation science literature (Grol, Wensing, Eccles, & Davis, 2013). Refer to Figure 1.1 to view the Grol and Wensing Implementation of Change Model.

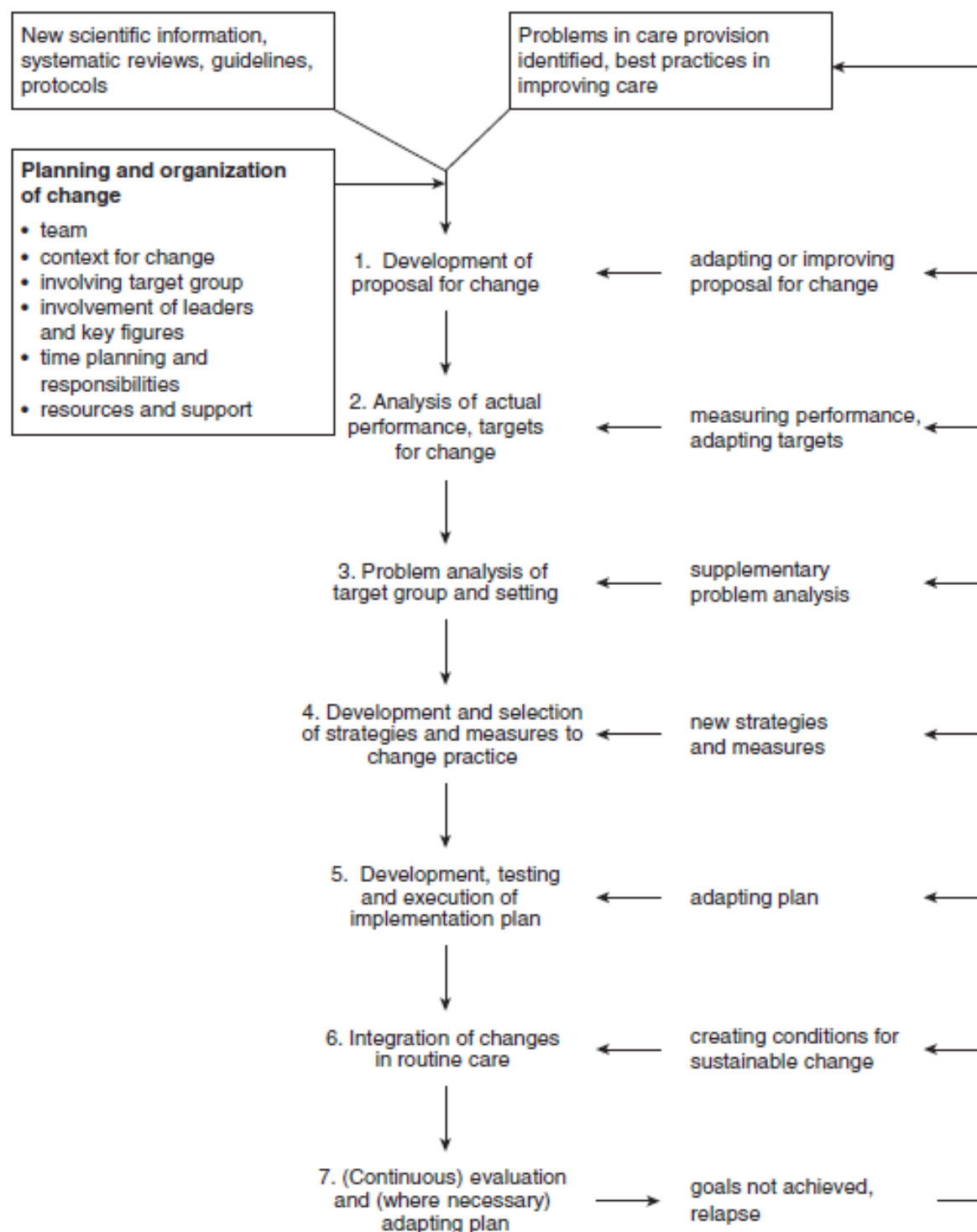


Figure 1.1 The Grol and Wensing Implementation of Change Model. Reprinted from Grol & Wensing (2013, p. 46). Used with permission.

The model includes seven steps. The aim of the first step of the model is to provide information to stakeholders regarding new strategies (e.g., practices or recommendations) that could be implemented. Step two includes examining the differences between current services provided and the strategies presented in step one. The purpose of step three is to understand the aims of the different stakeholder groups and to explore facilitators and barriers to change. Step four consists of choosing one of the strategies identified in step one or combining multiple strategies. The aim of step five is to work with a team of stakeholders to implement the strategy. Step six focuses on integrating the strategy into routine practice. Finally, step seven includes ongoing evaluation of the whole process and outcomes, and adapting efforts at each step of the model, as needed.

Evaluation of Conceptual Models

Although there are a multitude of models for implementing change, research is required to evaluate these models, in applied settings (Graham et al., 2007; Grol, Wensing, Bosch, et al., 2013; Tabak et al., 2017). Although researchers have explored strategies to promote the use of knowledge in practice, minimal research has been conducted that examines the concrete activities involved in incorporating knowledge into practice and policy (Grimshaw et al., 2012). Evaluation should be an ongoing process that takes place throughout knowledge mobilization activities (Gaglio & Glasgow, 2017). By documenting and understanding how to effectively incorporate research into practice, researchers can provide information regarding the utility of models for affecting change (Graham et al., 2007; Kothari et al., 2017). As Mitton and colleagues (2007) stated, “there is insufficient evidence for conducting evidence-based knowledge translation” (p. 756). In other words, there is little evidence indicating what activities

are effective for sharing knowledge and implementing change in different contexts (Kothari et al., 2017; Mitton et al., 2007). Thus, there is a need for more systematic research evaluating knowledge mobilization and implementation models and exploring which strategies should be used in different contexts (Mitton et al., 2007; Worton et al., 2017). These models tend to consist of sets of activities that can be implemented within applied settings, with a long-term goal in mind. Essentially, implementation and knowledge mobilization models outline the steps for implementation of programs. There are multiple types of evaluation that can be applied at different points in the implementation of a program or the implementation of change models. Below we provide a brief overview of common types of evaluation and provide a rationale for why we chose to conduct a process evaluation.

Types of evaluation.

It is important to understand the different types of evaluation in order to select one that is appropriate for the intended evaluation purpose. A formative evaluation examines the feasibility of a program (or in our case, this would be an implementation of change model) before implementation, and is typically conducted when it is being developed in order to make improvements (Centers for Disease Control and Prevention, 2014; University of Minnesota, 2019). A process evaluation examines whether program activities are implemented as intended and provides information that can be used to improve implementation activities (Centers for Disease Control and Prevention, 2014). A process evaluation is conducted throughout implementation (Centers for Disease Control and Prevention, 2014). An outcome evaluation measures the effects the program has on the target population (Centers for Disease Control and Prevention, 2014); it measures changes in intended outcome components (e.g., behaviour,

comprehension, attitudes; University of Minnesota, 2019). An impact evaluation assesses how effective the program is at achieving its long-term goals and sustained changes (Centers for Disease Control and Prevention, 2014; University of Minnesota, 2019). Evaluators should select the evaluation type based on the questions they want to answer.

Process evaluation.

The process of moving knowledge into practice and implementing change is complex and dynamic, and research examining these methods is limited (Graham et al., 2007; Kothari et al., 2017; Straus et al., 2011). The delivery of the steps of implementation of change models, and the experiences the stakeholders have during this process, can affect whether or not change in practice occurs (Hulscher, Laurant, & Grol, 2013). Thus, continuous monitoring and evaluation of the knowledge mobilization process is crucial (Braspenning et al., 2013). A process evaluation aims to describe the process involved in incorporating research knowledge into practice, the activities that were actually engaged in, and the experiences of different stakeholders throughout the process (Hulscher et al., 2013). A process evaluation can examine strategy fidelity, which is the degree to which implementation activities are performed as intended, and is able to elucidate the mechanisms and aspects of an implementation model that lead to improvements in practice (Hulscher, Laurant, & Grol, 2013). Evaluation data can be collected during scheduled events throughout the knowledge mobilization process, using a variety of methods. For example, data can be obtained through methods such as meeting minutes, group discussions, interviews, observations, and questionnaires (Bennet et al., 2007). Implementation and evaluation methods will depend upon the context in which knowledge mobilization is occurring (Gaglio & Glasgow, 2017) and should be informed by such factors as knowledge users' perspectives and

organizational characteristics (Wensing, Bosch, & Grol, 2013). Given the lack of research examining knowledge mobilization within community-based services, and the dynamic and multi-faceted context this setting provides, it is important to explore knowledge mobilization processes within this environment. Therefore, this dissertation focuses on knowledge mobilization in community-based organizations.

Knowledge Mobilization in Community-Based Organizations

Community-based organizations are public or private not-for-profit organizations that aim to improve life for local residents (Government of California, 2019; Government of Ontario, 2019). There are a variety of community-based organizations that provide different services, including social and health services. Community-based health organizations provide health promotion programs to improve community health, rather than providing primary clinical care to individual patients (Government of Ontario, 2019). Community-based social service organizations provide programs for individuals who are at risk of social exclusion, such as those with disabilities or mental illness (Canadian Observatory on Homelessness, 2018; PBWORKS, 2019). When conducting knowledge mobilization within community-based organizations, there are a variety of stakeholders who may be involved, including board members, staff (e.g., management, front-line workers), volunteers, service-users, and other community members (Worton et al., 2017). Implementation research in community-based settings is limited (Hardwick, Anderson, & Cooper, 2015). There is a need to evaluate knowledge sharing activities across community-based services in different sectors to develop more effective knowledge mobilization efforts (Hardwick et al., 2015; Worton et al., 2017).

Knowledge mobilization activities need to be adapted based on the knowledge being shared, the stakeholders involved, and the purpose of knowledge mobilization efforts (Ward, 2017). Our review of the literature indicates that the majority of research evaluating knowledge sharing and implementation approaches continues to be conducted within the health sciences. The majority of implementation research in the health sciences relates to clinical health settings, settings in which clinicians (e.g., physicians, nurses, etc.) provide direct treatment to patients to improve individual health. However, there is an increasing focus on knowledge mobilization in community-based health settings. Knowledge mobilization and implementation strategies likely differ in community-based health settings compared to clinical health settings (Contandriopoulos, Lemire, Denis, & Tremblay, 2010; Hardwick et al., 2015).

Given that there is limited research on knowledge mobilization in community-based social services, we can draw on the similarities and differences between community-based health and clinical health settings to inform knowledge mobilization in community-based social services. When doing so, it is important to be aware of the underlying differences between clinical and community-based settings, with regard to stakeholder knowledge, interpersonal dynamics, structure and function of operations, funding of services, and the political and societal aspects that impact the local context. Identifying factors that influence knowledge mobilization processes across contexts can inform practical knowledge mobilization strategies when engaging in knowledge mobilization in community-based services.

Factors that influence knowledge mobilization

Stakeholder characteristics and goals.

A variety of stakeholder characteristics have been identified as barriers and facilitators

when engaging in knowledge mobilization, including their skills, knowledge, self-efficacy, motivation, commitment, and opinions about interventions (Harrison et al., 2010; Kersten et al., 2018; The SURE Collaboration, 2011). Some researchers argue that personal attributes, such as intellectual ability, capacity, and learning styles should be considered, as they can vary between stakeholders and influence the way that knowledge mobilization activities should be carried out (Damschroder et al., 2009). Knowledge mobilization activities need to be cognitively accessible to key stakeholders; activities may need to be adapted so that the cognitive demands they impose match the cognitive capacities of involved stakeholders.

Another stakeholder factor that appears to be particularly relevant to community-based settings relates to how individuals intend to use the knowledge that is shared, as this varies across individuals and across settings (Worton, Loomis, Pancer, Nelson, & Peters, 2017). For example, while some stakeholders view knowledge sharing activities as an opportunity to exchange information with their peers, others want concrete information on how to implement new or adapt existing strategies (Worton et al., 2017). Understanding stakeholders' goals for knowledge will inform how knowledge can be used. Variations amongst knowledge mobilization goals will likely fluctuate across stakeholder groups and between community-based settings.

Stakeholder interactions.

Interactions within and between stakeholder groups can influence their perspectives and consequent behaviour. Therefore, it is crucial to examine the influence that different stakeholders have on one another (Damschroder et al., 2009). Examining factors such as how often stakeholders communicate, the type of information they discuss, and power dynamics within and between groups will provide crucial details regarding the ways in which stakeholders may affect

each other. Stakeholders' opinions about one another can be a barrier or a facilitator to knowledge mobilization. For example, lack of trust between stakeholder groups (e.g., between researchers, policy makers, and administrators) is an identified barrier to knowledge mobilization (Shooshtari, 2012), whereas strong relationships between stakeholder groups is a facilitator (Hardwick et al., 2015). Stakeholders' behaviour can be influenced by the opinions of others; implementation research within the health sciences indicates that health care professionals' behaviours can be influenced by their peers' and patients' opinions, ultimately affecting uptake of an improvement (Wensing et al., 2013). Clearly there is a need to have a thorough understanding of the interpersonal dynamics within and between knowledge user groups and to adapt knowledge mobilization activities to capitalize on facilitators and reduce barriers related to stakeholder relationships.

Knowledge users have indicated that communication within and between groups facilitates knowledge mobilization (Shooshtari et al., 2014). This may in part be because team meetings and teamwork facilitate knowledge sharing (Kersten et al., 2018). Unsurprisingly, lack of prioritization of meetings by service-providers has been identified as a barrier to knowledge mobilization (Kersten et al., 2018). Similarly, inconsistent communication between clinicians reduces their ability to implement new practices to support service-users (Wood et al., 2014). Although ongoing communication is clearly a facilitator to knowledge mobilization, different knowledge users may need to participate in different ways. Thoroughly understanding the characteristics of and interpersonal dynamics between each stakeholder group will foster productive collaboration and more effective knowledge mobilization.

Organizational factors.

Structure. When conducting knowledge mobilization activities, one must be informed about the structure of an organization, as different structures offer diverse functions and have varying advantages and disadvantages (Cameron & Green, 2009; Damschroder et al., 2009). Understanding the local organizational structure will help contextualize current practices and identify barriers and facilitators to knowledge mobilization at the organizational level.

In addition to the broad organizational structure, there are a variety of types of teams that can be in place within an organization (Cameron & Green, 2009). The size and composition of teams within an organization may influence knowledge mobilization activities (Wood et al., 2014). Ongoing support and input from management has been highlighted as a facilitator to knowledge mobilization (Kersten et al., 2018), and strong leadership on teams facilitates effective practice change (Wood et al., 2014). Lack of communication between managers and their employees was associated with reduced job practice changes during organizational change at a non-profit organization; employees emphasized the need for supervision during this process (Parlalis, 2011). Because staff tend to experience less stress when they receive more support from managers, additional support during implementation of change can foster this process (Cameron & Green, 2009; Thompson & Rose, 2011). Additionally, employees require information about changes and should be involved in implementation of change in order to increase uptake (Alvesson & Sveningsson, 2008; Cameron & Green, 2009). Furthermore, managers must also be able to effectively work in the context of planned change and adapt their behaviour when change occurs for change efforts to be successful (Alvesson & Sveningsson, 2008). This means that managers also need to be supported through the change process, by

receiving adequate training (Cameron & Green, 2009).

The importance placed on adequate training, frequent supervision, and strong communication during organizational change indicates that when planned change is occurring within an organization, it would be useful to adapt management practices and develop teams to help accommodate change. A change team, which coordinates activities and implements change, can be formed to facilitate a planned change initiative (Cameron & Green, 2009). Given the importance of collaborating with stakeholders when engaging in knowledge mobilization and implementation of change, it can be useful to form a change team that consists of individuals from a variety of employees in different roles (Cameron & Green, 2009). A change team can be used as a resource to help identify facilitators and barriers to knowledge mobilization and implementation of change and provide recommendations for tailoring knowledge mobilization activities to align with knowledge users' perspectives.

Turnover. There tends to be high employee turnover in community-based organizations, which likely leads to the need for additional staff training as knowledge mobilization processes move forward (Hardwick et al., 2015). The impact of turnover will vary depending on the structure and size of the organization, yet it is an important consideration, given that KM relies on motivated individuals.

Culture. Organizational culture refers to the assumptions underlying day-to-day behaviour within an organization, values that dictate how the organization should function, and established practices and behavioural norms (Alvesson & Sveningsson, 2008; Davies, Nutley, & Mannion, 2000). Because it is a difficult concept to define and is not easily measurable, it is important to identify concrete experiences that exemplify organizational culture (Alvesson & Sveningsson,

2008). Organizational culture can be studied by directly asking questions to stakeholders and by observing their day-to-day behaviour (Alvesson & Sveningsson, 2008).

Part of organizational culture includes perceptions about whether or not the organization is ready to change (Vakola, 2013). For organizational change to be successful, service-providers must adapt their values to align with new organizational values (Thompson & Rose, 2011). Essentially, a shift in organizational culture must occur for change to be effective (Alvesson & Sveningsson, 2008; Thompson & Rose, 2011). When scientific evidence contrasts with organizational culture, knowledge users tend to prioritize organizational culture, which can be a barrier to uptake of research knowledge (Dolcini et al., 2010; Hardwick et al., 2015). With regard to the health sciences, there are differences in the way that clinical and community-based organizations function and there are variations in their goals. For example, while clinical health settings tend to focus on changing practitioner behaviours to improve individual patient outcomes, community-based health settings emphasize collaboration with community members and other organizations to affect individual, community, and population outcomes (Hardwick et al., 2015; Kothari & Armstrong, 2011). Understanding organizational goals is important to inform knowledge mobilization strategies.

Another crucial aspect to consider is the way in which different types of knowledge are perceived by different organizations. The perspectives in community and clinical health settings tend to differ with regard to what they consider to be valuable knowledge (Worton et al., 2017). For example, within clinical health settings, randomized clinical trials are considered the optimal form of evidence (Kothari & Armstrong, 2011). Whereas, community-based organizations tend to prioritize experiential knowledge of service-providers, service-users, and community

members, over scientific research (Hardwick et al., 2015; Montesanti, Abelson, Lavis, & Dunn, 2015; Worton et al., 2017). This may be because there tends to be less available research that appears applicable to community-based settings, and the perspectives of service-providers and service-users are often deemed to be more contextually relevant (Hardwick et al., 2015; Kothari & Armstrong, 2011). Service-providers have indicated that existing research evidence often does not address how to implement interventions with marginalized populations (Montesanti et al., 2015). Findings from research conducted within the local organization may be more highly valued because they are viewed as more contextually relevant than research conducted elsewhere (Kothari & Armstrong, 2011). When collaborating with community-based social service organizations, it is important to identify the types of knowledge and perspectives they value and incorporate these sources into the knowledge mobilization process.

Resources. Lack of financial resources is a common barrier to knowledge mobilization in community-based settings (Hardwick et al., 2015). Although financial incentives can be a motivator for practice change within the clinical healthcare sector (Wensing et al., 2013), this is typically not a viable option for non-profit organizations that tend to have less financial resources while facing the need for more services for the community (Schalock & Verdugo, 2013). Moreover, smaller organizations with fewer resources will likely be unable to spend more funds and hire additional staff, which is often needed to implement organizational change (The SURE Collaboration, 2011). Given the lack of available resources, community-based organizations may use knowledge shared during knowledge mobilization efforts to inform their perspectives or improve existing programs, rather than implementing new strategies (Worton et al., 2017).

Volunteers. Community-based organizations often rely on volunteers to function (Balandin, Llewellyn, Dew, & Ballin, 2006; Cherrington et al., 2010; Manetti, Bellucci, Como, & Bagnoli, 2015). Although thorough training is necessary to perform tasks effectively, lack of resources leads to insufficient training for many volunteers (Balandin et al., 2006). This likely leads to inadequate service provision. The reliance on volunteers appears to play a bigger role at community-based social service organizations compared to clinical health settings. Thus, when conducting knowledge mobilization activities in community-based organizations, it is crucial to consider the role of volunteers in the provision of organizational services.

Despite the important role that volunteers play within community-based organizations, there is minimal knowledge mobilization research that discusses how to effectively include volunteers in knowledge mobilization activities. In the few papers we found regarding volunteer involvement in knowledge mobilization, volunteers had much lower response rates than paid staff (Gainforth, Latimer-Cheung, Athanasopoulos, Moore, & Ginis, 2014; Gainforth, Latimer-Cheung, Moore, Athanasopoulos, & Martin Ginis, 2015), and on one occasion their responses were excluded from data analysis due to these low response rates (Gainforth et al., 2014). It was speculated that lower response rates from volunteers might have been due to less investment in knowledge mobilization research or the research tool was not as accessible to volunteers (Gainforth et al., 2015). This suggests that when involving volunteers in knowledge mobilization, they should be engaged with differently than organizational staff. However, it is unclear how to most effectively include them. When conducting knowledge mobilization in community-based organizations where volunteers are deemed to be key stakeholders, is important to evaluate potential facilitators and barriers to their involvement.

Community connections.

The degree to which the organization is connected with others in the community can impact knowledge mobilization efforts (Damschroder et al., 2009). It is important to be aware of any other organizations within the community that provide services to the target service-users, the focus of their services, and how they impact service-users' needs. In addition to considering the other community supports that are available, it is crucial to be aware of how services provided by the local organization may be perceived by external community members who are affected by the services in some way. For example, decisions made during knowledge mobilization activities may be hindered if external stakeholders stigmatize recipients of social services. Groups that are supported by community-based organizations often experience stigmatization, such as individuals with mental illness and people experiencing homelessness, (Corrigan, Bink, Fokuo, & Schmidt, 2015; Jahoda, Wilson, Stalker, & Cairney, 2010; Weisz & Quinn, 2018). The way that stakeholders in the local community perceive and interact with service-users can inform knowledge mobilization and implementation efforts that take place within the community and involve other community members.

Societal and political factors.

Schalock and Verdugo (2013) made an apt commentary on current widely held beliefs, "We live in a transformational era that focuses on change and creating value through innovation" (p.274). This societal view contributes to the broad context that knowledge mobilization efforts are taking place within. There is a strong value placed on implementation of change across sectors (Schalock & Verdugo, 2013; Worton et al., 2017), which is likely why research in community-based setting has tended to focus on the later phases of implementation, rather than

knowledge sharing practices that may be more relevant to community-based settings (Worton et al., 2017). In addition to societal beliefs, systemic and political circumstances impact stakeholder views and can influence the knowledge mobilization process (Meyers et al., 2012). For example, changes made by funding and regulatory bodies will affect organizational practices (Schalock & Verdugo, 2013). Additionally, legislation and policies may be a catalyst or impetus for change (Alvesson & Sveningsson, 2008; Roberts et al., 2013). Although there is limited research on how laws and regulations influence knowledge mobilization and implementation (Damschroder et al., 2009; Wensing et al., 2013), it is evident that they impact stakeholder perspectives and priorities.

The Case of Friendship Support for Adults with Intellectual Disabilities

In Ontario, community-based organizations provide most social services for individuals with intellectual disabilities (Government of Ontario, Ministry of Community and Social Services, 2015). For this dissertation, we evaluated knowledge mobilization activities in a community-based setting to improve services for individuals with intellectual disabilities. Studying knowledge mobilization to support individuals with intellectual disabilities highlights some of the complexities that should be considered within community-based services, such as working with a variety of stakeholder groups, including individuals who may be marginalized and vulnerable to social exclusion. There is an ongoing self-advocacy movement regarding the importance of having individuals with intellectual disabilities contribute to research to ensure that services they receive are relevant to their needs (Stack & McDonald, 2014). Thus, it is crucial that their voices are heard when developing and adapting services for them. Additionally, community-based organizations that support adults with intellectual disabilities often interact with and support both the adults and their family members, so it is important to include family

members and relevant caregivers in the knowledge mobilization process. Furthermore, service-providers and front-line workers often come from a variety of work and educational backgrounds. In the context of community-based settings, there is a multitude of stakeholders who can and should contribute important and varying types of knowledge in order to make well-informed decisions regarding services and supports adults with intellectual disabilities.

Description of intellectual disabilities.

Intellectual disability is characterised by deficits in intellectual functioning (e.g., problem solving, abstract thinking, planning) and adaptive functioning (e.g. abilities related to conceptual, social, and practical life skills; American Psychiatric Association, 2013). These deficits are associated with problems in communication, social participation, and personal independence, which affect daily activities (American Psychiatric Association, 2013). Intellectual disability can include individuals with diagnoses such as Down syndrome, Fetal Alcohol Syndrome, Prader-Willi syndrome, Fragile X Syndrome, and Autism Spectrum Disorder. Intellectual disability arises during childhood or adolescence (American Psychiatric Association, 2013) In 2010, approximately 0.8% of Ontario residents, between 18 and 64 years of age, had an intellectual disability (Lin et al., 2014).

There are a variety of terms used to describe individuals who have the above outlined characteristics. In the *Diagnostic and Statistical Manual of Mental Disorders, 5th Edition* (American Psychiatric Association, 2013), the term “Intellectual Disability” is used, while the *International Classification of Diseases, 11th Edition* uses the term “Disorders of Intellectual Development” (World Health Organization, 2016). “Mental Retardation” was used in the *International Classification of Diseases, 10th Edition* (World Health Organization, 1992) and in

the *Diagnostic and Statistical Manual of Mental Disorders, 4th Edition* (American Psychiatric Association, 2000), but this term is now considered pejorative. In the scientific literature, terms such as “Intellectual and Developmental Disability”, “Developmental Disability”, and “Learning Disability” are also used to describe this population, depending on geographical location and researcher background. For example, “Learning Disability” is used in the United Kingdom; however, this term is not used in North America as it denotes a different diagnosis. In this dissertation, the acronym ID will be used to denote “Intellectual Disabilities”, which refers to individuals who experience deficits in intellectual and adaptive functioning.

Social lives of individuals with intellectual disabilities.

Individuals with ID often experience challenges with social functioning due to deficits in intellectual and adaptive functioning. For example, difficulty planning and problem solving can interfere with a person’s ability to travel independently to attend organized activities or meet up with friends. Furthermore, some individuals do not have the communication abilities or social skills to effectively initiate and maintain social connections. Individuals with ID are also at higher risk of experiencing exploitation and abuse and may experience limited autonomy due to their or others’ fear of harm (Healy et al., 2009; Hollomotz, 2009). Likely due to the above-mentioned barriers, adults with ID tend to have fewer opportunities to make friends and experience high levels of loneliness (Hurd, Evans, & Renwick, 2018; Scott & Haverkamp, 2018). Having satisfying friendships is associated with higher quality of life for adults with intellectual disabilities (ID); high quality friendships are associated with having better mental and physical health, feeling more respected and being treated more fairly, exercising more choice, and experiencing more community integration (Friedman & Rizzolo, 2018; Scott & Haverkamp, 2018; Spassiani, Parker Harris, & Hammel, 2016). Individuals with ID often require additional

support to form meaningful ties with others in their community (Fulford & Cobigo, 2016). Given the numerous benefits associated with having friendships, it is essential that we implement effective friendship support services.

Social services for individuals with intellectual disabilities.

Our research activities took place in the context of a change to numerous regulations and policies that impact funding and available social supports for adults with ID. Over a decade ago the United Nations (2006) *Convention on the Rights of Persons with Disabilities* recognized that persons with disabilities have the right to full community inclusion (article 19), which impacted the international context regarding the rights of individuals with ID. At the federal level, the Government of Canada ratified the convention, committing that the country would support the rights of those with disabilities (Employment and Social Development Canada, 2017). At the provincial level, the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act* (Government of Ontario, 2008) highlighted the importance of social inclusion, independence and choice, which facilitate friendship development.

Given that social support and friendships are crucial for good mental well-being, the provincial and federal governments provide funding for social support services for adults with ID. Specifically, the Government of Ontario (2013) funds services through community-based organizations, which provide opportunities for adults with ID to socialize and form friendships. The Government of Ontario also provides direct funding to adults with ID to pay for supports for community participation (Government of Ontario, 2018). Many adults with ID use this funding to pay for services provided by community-based organizations. Community-based organizations for individuals with ID in Ontario promote community inclusion in areas related to residential

support, employment, and social participation (Government of Ontario, Ministry of Community and Social Services, 2015). Through the *Social Development Partnerships Program – Disability Component*, the Government of Canada (2015) funds initiatives aimed at addressing social needs of persons with disabilities.

Policies and funding directly impact the financial resources available to community-based organizations and the finances available for persons with ID to spend on these services. Adults with ID in Ontario receive direct funding to pay for services of their choosing; therefore, there is less government funding provided directly to community-based organizations that provide these services. Consequently, these organizations may not have the financial flexibility to easily implement changes to their services or programs. It may also mean that service-users have more decision-making power than in sectors with other funding models, given that they choose what services they want to pay for and where to access those services.

Friendship support for individuals with intellectual disabilities.

Community-based organizations that support individuals with ID play a crucial role in meeting their friendship-related support needs. Individuals with ID often require practical, informational, and/or emotional support to have friendships (Fulford & Cobigo, 2016; Inclusive Research Network, 2010; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Community-based organizations can provide practical friendship support by offering spaces where individuals can spend time with one another (Mason, Timms, Hayburn, & Watters, 2013). Regarding informational support, service-providers can provide guidance on topics such as how to use the internet to stay in touch with friends (Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014) and how to use public transit to visit friends (Weafer, 2010). Moreover, when individuals with ID require emotional support, service-providers can encourage and assist service-users to

call upon members of their social network (Asselt-Goverts et al., 2014). Individuals with ID have also emphasized the importance of talking with service-providers and seeking advice about their relationships (Asselt-Goverts et al., 2014; Bane et al., 2012; Mason et al., 2013; Rushbrooke, Murray, & Townsend, 2014). Community-based organizations are a crucial resource for facilitating friendships for adults with ID.

Knowledge mobilization to support friendships.

Although many adults with ID receive friendship support from community-based organizations, they continue to desire more friendships and want to see their friends more frequently (Friedman & Rizzolo, 2018). Friendship development is important to individuals with ID (Fulford & Cobigo, 2016), yet implementing effective friendship interventions is a challenge for service-providers (Emerson & McVilly, 2004; Lippold & Burns, 2009). There is a paucity of research regarding how to effectively facilitate friendships for individuals with ID (Scott & Haverkamp, 2018). There is a need to incorporate existing research knowledge into practice, regarding how to support friendships among individuals with ID, as this can lead to improvements in the supports provided by community-based organizations. By collaborating with stakeholders and sharing different types of knowledge, service-providers at community-based organizations will be better equipped to support friendships, thereby enhancing the wellbeing of individuals with ID.

Research Objective and Questions

The current dissertation was an implementation science project; the objective was to conduct an evaluation of a knowledge mobilization process in a community-based organization that supports individuals with ID. We refer to ‘knowledge mobilization’ in the following

chapters because this term emphasizes the reciprocal exchange of knowledge amongst stakeholders (Government of Canada, 2018), which was a key focus throughout this dissertation. We conducted a process evaluation, rather than focusing on evaluating outcomes related to changes in practice, to better understand the intricacies of knowledge mobilization activities within the dynamic context of community-based services. The aim of the project was to understand how stakeholders share knowledge, use knowledge, and collaborate to make decisions regarding practices. The over-arching process evaluation questions were:

- 1) How were knowledge mobilization activities implemented in community-based services for individuals who are vulnerable to social exclusion?
- 2) How were knowledge mobilization activities implemented in community-based services involving multiple levels of stakeholders?

SECTION 2: Fostering Friendships for Individuals with Intellectual Disabilities

The research activities conducted for this dissertation aligned with the Grol and Wensing Implementation of Change Model (2013). The model included seven steps. The current section aligned with the first step of the model. The aim of the first step was to collate and present information regarding the topic of focus and potential strategies (e.g., practices or recommendations) that could be implemented. Therefore, this section [Chapters 2 and 3] contained a substantive review of the current literature on friendships and friendship support strategies for adults with intellectual disabilities. [For detailed information regarding the steps of the Grol and Wensing (2013) model, refer to Chapter 4.]

**Chapter 2: Friendships and Intimate Relationships among People with Intellectual
Disabilities: A Thematic Synthesis**

Fulford, C., & Cobigo, V. (2016). Friendships and Intimate Relationships among People with Intellectual Disabilities: A Thematic Synthesis. *Journal of Applied Research in Intellectual Disabilities*, 31(1), e18–e35. doi:10.1111/jar.12312

Contribution

Author Contributions

Casey Fulford, the primary author, conducted the systematic literature search, completed data analysis and wrote the majority of the content.

Dr. Virginie Cobigo, the supervising author, met with Ms. Fulford frequently to discuss the research questions, search strategy, and data analysis. Throughout the process, Dr. Cobigo provided guidance and recommendations regarding article content and edited the full paper.

Funding

There was no funding provided for the completion of this paper.

Preamble

This paper provides a rationale for why we selected the case of supporting friendships for individuals with intellectual disabilities (ID) to explore knowledge mobilization (KM) in community-based services. The following literature review presents details on how individuals with ID conceptualize friendships and romantic relationships, and discusses their perceptions regarding the facilitators and barriers to these relationships. The paper emphasizes the importance of meaningful relationships within the lives of individuals with ID; the barriers they face in developing and maintaining relationships; and the key social supports that community-based services provide, despite the lack of resources and knowledge at their disposal.

Inclusion of Romantic Relationships

Although romantic relationships are discussed in this article, the remainder of this dissertation focuses specifically on friendships. Romantic relationships are an important aspect of the social lives of individuals with ID and there is overlap in the barriers individuals with ID experience to having these relationships; however, there are some differences in the skills required to initiate and maintain friendships and romantic relationships. Thus, it is likely that varying interventions would be used to facilitate these different types of relationships. Therefore, we ultimately chose to focus on friendships for this dissertation in order to have a more specific range of services to consider when engaging in KM activities.

Inclusion of Age 14 and Older

In the methods section of this article, we indicated that “fourteen years of age was selected because, during the early/middle teens, people usually start focusing on romantic feelings, in a manner which is distinctly different from childhood (Miller & Benson, 1999)”. Although, younger children could also talk about friendships, we expect that strategies to support

relationships at younger ages would be school-based. Given that this dissertation focused on strategies in community-based settings, we opted to include participants who were fourteen years of age or older to ensure that the perspective we were seeking was relevant to informing community-based supports. Furthermore, at the time this literature review was conducted, we were considering including participants who were in high school, which was another argument for including participants who were at least 14 years old.

Additional Figures Explaining Search Process

See Appendix A for figures that provide a detailed breakdown of the systematic literature search process and the reasons articles were excluded from the literature review.

Abstract

The purpose of this thematic synthesis was to review qualitative studies on perspectives of persons with intellectual disabilities (ID) regarding friendships and intimate relationships. A literature search was conducted, including studies published between 2004 and 2014, involving participants 14 years of age or older, who had ID, and participated in focus groups or interviews. Eighteen studies were included. Three master themes were identified: 1) How do I know someone is my friend, 2) How do I know someone is my boyfriend or girlfriend, and 3) What helps and hinders relationships. Understanding how people with ID describe relationships, and being aware of factors that support and impede relationships, will aid stakeholders in developing training, policies, programs, and services. Knowledge translation of research that focuses on strategies aimed at supporting relationships is crucial to affect change in applied settings and improve quality of life for persons with ID.

Introduction

Research supports that social relations are beneficial to psychological wellbeing (Kawachi & Berkman, 2001). Social support is a protective factor which enhances mental (Hefner & Eisenberg, 2009; Marmot & Wilkinson, 2005) and physical health (Marmot & Wilkinson, 2005). Conversely, social isolation and having fewer friendships is associated with lower wellbeing (Marmot & Wilkinson, 2005) and increased likelihood of mental health problems (Fiori, Antonucci, & Cortina, 2006). Additionally, those living without significant others are more likely to report lower quality of social support (Hefner & Eisenberg, 2009), which is associated with lower quality of life (Lunsky & Benson, 2001).

Similarly, among individuals with intellectual disabilities (ID), mental and physical health problems may be exacerbated by feelings of loneliness (Gilmore & Cuskelly, 2014). Those who experience more feelings of love in intimate relationships have higher emotional wellbeing (Arias, Ovejero, & Morentin, 2009). However, persons with ID are less likely to receive emotional support (Havercamp, Scandlin, & Roth, 2004) and report higher levels of loneliness (Bhaumik, Tyrer, McGrother, & Ganghadaran, 2008), as well as those who see their friends less frequently (McVilly, Stancliffe, Parmenter, & BurtonSmith, 2006).

Many persons with ID value their friends and express a desire for more friendships (Cummins & Lau, 2003; Healy, McGuire, Evans, & Carley, 2009). They also want intimate relationships (e.g. boyfriend/girlfriend), and many think marriage is important (Healy et al., 2009; Knox & Hickson, 2001). Largely due to self-advocacy, there has been a movement to promote relationship rights for persons with ID (Löfgren-Mårtenson, 2004). The United Nations *Convention on the Rights of Persons with Disabilities* (2006) states that persons with disabilities

have the right to full community inclusion (article 19), intimate relationships (article 23), and marriage (article 23). The convention emphasizes the importance of freedom of choice (article 3) and facilitating peer support (article 24). Many governments have published legislature and reports promoting social inclusion and relationship development for persons with ID. For example, *Valuing People Now* (Department of Health, 2007 in London, England) promotes enabling persons with ID to develop friendships and relationships with a wider range of people. *The Same as You* (Scottish Executive, 2000) states that individuals with ID should be provided with support to meet their relationship needs.

As evidenced above, there have been major strides forward in promoting the rights of persons with ID. However, opportunities to develop relationships are still limited (Healy et al., 2009). Adults with ID tend to have small social networks in which social support is provided by caregivers, such as staff and family members (Lippold & Burns, 2009). People with ID are frequently socially isolated (Department of Health, 2001). A major challenge for services that support persons with ID, is helping service-users maintain friendships and avoid social isolation (Department of Health, 2001). Staff and family caregivers have indicated that they need more training to support relationships of persons with ID (Evans, McGuire, Healy, & Carley, 2009). Thus, there is a need to understand how caregivers can better support the development and maintenance of friendships and intimate relationships for this population. Stakeholders need to understand how persons with ID define relationships in order to develop policies, programs, and services which meet the needs and fulfill the rights of those with ID. It is also important to understand which factors support and impede relationship development and maintenance, for these individuals, to enable caregivers to better assist persons with ID (Emerson & McVilly, 2004).

The purpose of this paper was to conduct a thematic synthesis which combines and examines data from qualitative studies, which report the perspectives of persons with ID. The aims of this review were to 1) explore how persons with ID describe friendships and intimate relationships, and 2) explore what persons with ID think the barriers and supports are to forming and maintaining these relationships. By better understanding the unique perspectives and experiences of individuals with ID, caregivers will be better equipped to support relationships and meet the needs of these individuals.

Materials and Methods

We focused on the perspectives of persons with ID because they are the experts regarding their experiences and opinions, and can provide a unique perspective (Knox & Hickson, 2001; Taylor, Lambeth, & Lives, 2007). Previous research findings indicate that focus groups and interviews can be conducted to aid in participation of persons with ID in research about their own opinions and experiences (Mactavish, Mahon, & Lutfiyya, 2000). Thus, a thematic synthesis following the method described by Thomas & Harden (2008) was conducted, to systematically synthesize qualitative research findings in order to integrate and interpret results from different studies.

Inclusion Criteria

Primary research studies, written in English, and published between January 2004 and December 2014, were included in this review. The starting date of 2004 was chosen to review recent research findings. Thematic syntheses are intended to provide a conceptual synthesis of the recent literature on a topic, and thus seek conceptual saturation, rather than exhaustiveness (Thomas & Harden, 2008). Studies involving participants with ID, who were 14 years of age or older, were included. Fourteen years of age was selected because during the early/middle teens

people usually start focusing on romantic feelings, in a manner which is distinctly different from childhood (Miller & Benson, 1999). We reviewed qualitative studies that used interviews and/or focus groups to explore the perspectives of individuals with ID about friendships and intimate relationships.

Search Strategy

The literature search included three phases: 1) a systematic database online literature search, 2) a hand search, and 3) a grey literature search.

Database search. We conducted separate keyword searches on the topics of friendships and intimate relationships. The search focusing on friendships consisted of (*"intellectual disability" OR "developmental disability" OR "learning disability" OR "mental retardation"*) AND (*"interpersonal relationship" OR "friendship" OR "friend"*). The search focusing on intimate relationships consisted of (*"intellectual disability" OR "developmental disability" OR "learning disability" OR "mental retardation"*) AND (*"romance" OR "romantic relationship" OR "marriage" OR "couple" OR "love" OR "intimate" OR "intimacy" OR "significant other"*). Databases searched included PsycINFO, PubMed, Academic Search Complete, and Web of Science. Papers from peer-reviewed journals, which met all inclusion criteria, were included. First, all titles were inspected. Then, abstracts of the relevant articles were read. Finally, the full articles were reviewed to determine if they met all inclusion criteria.

Hand search. The references cited in articles that were included from the online database literature search, underwent a title, abstract, and full article review. Articles which met all inclusion criteria were included.

Grey literature. The grey literature search included Google searches, using combinations of terms that were used in the database literature review. Studies which met all inclusion criteria were included.

Quality Assessment

Prior to completing the thematic synthesis, quality assessments were conducted on all studies, using the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Singh, 2013). We added an additional question to the CASP Qualitative Research Checklist because it has been suggested that qualitative research should include procedures for establishing validity (Creswell & Miller, 2000). Both authors independently assessed each paper and then resolved disagreements through discussion. We scored articles by examining if and how the written content answered the questions on the CASP Qualitative Research Checklist. Because there is minimal evidence for deciding how to exclude articles based on quality assessment (Thomas & Harden, 2008), studies were not removed based on the quality assessment scores.

Data Extraction and Analysis

The method for data extraction and analysis was informed by Thomas and Harden (2008). Text in the results section of each study, which directly related to the perspectives of people with ID, regarding friendships and intimate relationships, was analyzed using QSR NVivo software. Initially, data analysis was conducted line-by-line, to form codes from segments of text. As each results section was coded, more extracts were added to the existing codes and additional codes were created when necessary. The coding scheme was constantly compared to the original texts to ensure that it was grounded in the data (Charmaz, 2006); no a priori coding structure was established. After all data were coded, codes were clustered to form themes. Themes were formed to synthesize the data and to organize concepts marked by similar

characteristics. A hierarchical structure of themes emerged throughout the coding process. The authors found common patterns across studies and assessed how themes and sub-themes interacted in order to answer the review questions. The senior researcher audited the first author's coding structure on a regular basis; points of disagreement were resolved through consensus and reviewing the raw data. Theoretical saturation was reached when all raw data from the results sections of included articles fit into established themes (i.e., no new codes or themes needed to be created; Charmaz, 2006).

Results

Study Characteristics

During the database search, initially 305 articles were found using the friendship search terms, and 955 articles were found using the intimate relationship search terms. After conducting title, abstract, and full article reviews, ultimately six articles from the friendship search and five articles from the intimate relationship search met inclusion criteria. Twenty articles were initially identified through the hand search, and six met inclusion criteria. One study meeting the inclusion criteria was found through the grey literature search. Ultimately, eighteen studies were included in the thematic synthesis. The majority of included studies were conducted in Europe (United Kingdom and Republic of Ireland). Sample sizes ranged from four to 168 participants, however the majority of studies used a sample size of less than 20. Table 2.1 describes the key characteristics of the reviewed studies and Table 2.2 provides the quality assessment scores of these studies.

Table 2.1. *Characteristics of Selected Studies*

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
Bane et al., 2012	Relationships and supports	Republic of Ireland	- Over 30: 42 - Under 30: 17 -38 people did not provide their age	N = 97, Female = 52 (54%), Male = 45 (46%), Learning disability	Focus groups	Developed and summarized themes. Then researchers discussed findings and compared to participant quotes.
Brackenbri dge & Mackenzie , 2005	Factors that contribute to (un)popularity	Scotland	M = 33.33, SD = 10.68	N = 24, Female = 13 (54%), Male = 11 (46%) Learning disability	Semi- structured interviews	Grounded theory
Eastgate et al., 2011	Women's sexual knowledge, relationship experience, and self-protection skills	Australia	R = 21-46 - 20 to 29: 2 - 30 to 39: 4 - 40 to 49: 3	N = 9, Female = 9 (100%), Intellectual disability, Mild (able to participate in an interview in English without support) <u>Living:</u> - Alone: 3 - With partner: 4 - In hostel: 1 - With family: 1	Semi- structured interviews	Analysis not specified
Fitzgerald, & Withers, 2013	Women's perceptions as sexual beings	United Kingdom	R = 19-64	N = 10, Female = 10 (100%), Intellectual disability, Able to communicate using speech	Semi- structured interviews	Thematic analysis

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
Kelly et al., 2009	Sexuality, romantic relationships, and assistance needed	Republic of Ireland	R = 23-41, M = 32	N = 15, Female = 7 (47%), Male = 8 (53%), Intellectual Disability	Focus groups	Thematic analysis was being undertaken. This was a preliminary analysis.
Lafferty et al., 2013	Couples relationships	Northern Ireland	R = 26-65, M = 47	N = 16 (8 couples), Female = 8 (50%), Male = 8 (50%), Learning disability <u>Living</u> - Supported living, with partner: 6 -Supported living, alone: 3 - Residential housing: 2 - With parent: 1 - Independent: 2 - Dispersed housing: 2	Dyadic and individual semi- structured interviews	Grounded theory
Mason et al., 2013	Friendship perceptions and experiences	England	R = 24-62, M = 42	N = 11, Female = 7 (64%), Male = 4 (36%), Learning disability <u>Living</u> - Alone: 6 - With spouse: 2 - Shared accommodation: 3	Semi- structured interviews	Interpretative phenomenological analysis

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
McVilly et al., 2006	Friendship experiences and aspirations	Australia	R = 23 - about 50	N = 11, Female = 5 (44%), Male = 6 (55%), Intellectual disability, limited to intermittent support needs and spoke in full sentences <u>Living</u> - Independently with regular support: 4 - Supported/group home: 3 - With parents: 4	Focus groups	Analysis not specified
National Institute for Intellectual Disability, 2009	Life of people with ID in Ireland	Ireland	-Under 30: 84 - 30 to 49: 59 - Above 49: 19 - 6 people did not report their age	N = 168, Female = 82 (49%), Male = 83 (51%), Intellectual disability	Focus groups	Developed themes, identified related themes, and chose important themes.
Pestka & Wendt, 2014	Belonging and abuse of women in intimate relationships	Australia	R= 21-69 - 20 to 30: 1 - 40 to 50: 2 - 60-70: 1	N = 4, Female = 4 (100%), Intellectual disability, Mild	Semi- structured interviews	Performative dialogical analysis

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
Rushbrooke, Murray, & Townsend, 2014	Sexuality and intimate relationships	England	R = 21-56, M = 31.7	N = 9, Female = 4 (44%), Male = 5 (56%), Learning/ Intellectual disability, Had capacity to consent <u>Living</u> - Supported accommodation: 5 - with parents: 2 - Independently, with staff support: 2	Semi- structured interviews	Interpretative phenomenological analysis
Sullivan et al., 2013	Experiences and perceptions of close sexual relationships	Scotland	- 31 to 40: 3 - 41 to 50: 3 - 51 to 60: 4	N = 10, Female = 4 (40%), Male = 6 (60%), Intellectual disability, Expressive language abilities <u>Living</u> - Family home: 7 - Own home: 3	Semi- structured interviews	Interpretive phenomenological analysis

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
The Money, Friends and Making Ends Meet Research Group, United Kingdom, 2012	Lives and experiences of people with learning disabilities	England	Age not stated	N = 11, Learning disability	One-to-one talks and group meetings	Grounded theory
Walter-Brice et al., 2012	Domestic abuse of women within intimate relationships	United Kingdom	R = 27-50	N = 5, Female = 5 (100%), Learning disability <u>Living:</u> - Council/supported accommodation: 4 - Private, rented: 1	Semi-structured interview	Interpretative phenomenological analysis
Ward, Bosek, Trimble, 2010	Dating, romantic relationships, and interpersonal violence	Alaska	R = 18-57 - 18 to 29: 7 - 30 to 39: 7 - 40 to 49: 6 - 50 to 59: 2	N = 47, Female = 22 (47%), Male = 25 (53%) Intellectual Disability, Not severe; sufficient verbal skills to participate. <u>Living</u> - Independent: 10 - Roommate: 7 - Other: 3 - Unreported: 2	Semi-structured interviews	Application of the Consensual Qualitative Research Model

Author(s) and Year	Focus	Country	Age of Participants in years (M: mean, SD: Standard Deviation, R: Range)	Sample Description (N, gender, diagnosis, level of functioning, living situation)	Method	Analysis
Wheeler, 2007	Men's sexuality and sexual identity	Whales	R = 16-42, M = 25.5	N = 12, Male = 12 (100%), Learning disability <u>Living</u> - With family member: 9 - Supported accommodation: 1 - Alone: 2	Semi- structured interviews	Interpretive phenomenological analysis
Yacoub & Hall, 2009	Men's sexual knowledge, experiences, and attitudes	United Kingdom	R = 19-65	N = 19, Male = 19 (100%), Learning disability, Mild <u>Living</u> - Independent: 8 - Residential: 2 - Secure hospital: 7	Semi- structured interviews	Constant comparative method
Yau et al., 2009	Sexuality	Hong Kong	R = 22-44	N = 12, Female = 9 (75%), Male = 3 (25%), Developmental disability, Mild <u>Living</u> - With family: 7 - Supported hostel: 5	Semi- structured interviews	Developed categories, collapsed into themes, inductive analysis used to check for contra-occurrences, Subsequent themes tested

*Note*¹. All studies did not contain the same ample description information (i.e., sample size, gender, diagnosis, level of functioning, and living situation). However, we have not explicitly stated when information was missing from the original articles, to make the table more legible. *Note*². Different terms are used to describe individuals with Intellectual Disability as described by the American Association on Intellectual and Developmental Disabilities (Schalock, 2010) depending on geographical location in which studies are conducted. Participants who are described as having a “learning disability” in the included studies would be diagnosed with an Intellectual Disability as described *Diagnostic and Statistical Manual of Mental Disorders (DSM), 5th Edition*. In this context, learning disability is not referring to individuals who have learning disorders, such as dyslexia or dyscalculia.

Table 2.2. *Quality Assessment of Selected Studies*

Author(s) and Year	A	B	C	D	E	F	G	H	I	J	K	Total
Bane et al., 2012	1	1	0	1	1	0	1	0	1	1	0	7
Brackenbridge & Mackenzie, 2005	1	0	0	1	0	0	0	0	1	0	0	3
Eastgate et al., 2011	1	1	0	1	1	0	1	0	1	0	0	6
Fitzgerald, & Withers, 2013	0	1	1	0	1	0	1	1	1	1	1	8
Kelly et al., 2009	1	1	0	1	1	0	0	0	1	0	0	5
Lafferty et al., 2013	1	1	1	1	1	0	1	1	1	1	1	10
Mason et al., 2013	1	1	1	1	1	0	1	1	1	1	1	10
McVilly et al., 2006	1	1	0	1	1	0	0	0	1	1	1	7
National Institute for Intellectual Disability, 2009	1	1	0	0	0	0	0	0	1	0	0	3
Pestka & Wendt, 2014	1	1	1	1	1	1	1	0	1	0	0	8
Rushbrooke, Murray, & Townsend, 2014	1	1	1	1	1	1	1	1	1	1	1	11
Sullivan et al., 2013	1	1	1	1	1	0	1	1	1	1	1	10
The Money, Friends and Making Ends Meet Research Group, United Kingdom, 2012	1	1	1	0	0	1	1	0	0	0	1	6
Walter-Brice et al., 2012	1	1	0	1	1	0	1	0	1	0	0	6
Ward, Bosek, Trimble, 2010	1	1	0	1	1	0	1	1	1	1	1	9
Wheeler, 2007	1	1	1	1	1	1	1	1	1	0	0	9
Yacoub & Hall, 2009	1	1	0	1	1	0	1	1	1	1	0	8
Yau et al., 2009	1	1	0	1	1	0	1	1	1	1	0	7

*Note*¹. A - Was there a clear statement of the aims of the research? B - Is qualitative methodology appropriate? C - Was the research design appropriate to address the aims of the research? D - Was the recruitment strategy appropriate to the aims of the research? E - Was the data collected in a way that addressed the research issue? F - Has the relationship between researcher and participants been adequately considered? G - Have ethical issues been taken into

consideration? H - Was the data analysis sufficiently rigorous? I - Is there a clear statement of findings? J - How valuable is the research? K - Is the data credible and validated?

*Note*². Criteria A through J are from the Critical Appraisal Skills Programme (CASP) Qualitative Research Checklist (Singh, 2013).

Themes

Three master themes were extracted from the data: 1) How do I know someone is my friend, 2) How do I know someone is my boyfriend or girlfriend, and 3) What helps and hinders relationships. Table 2.3 provides the structure of master and sub-themes, as well as supporting quotes.

Table 2.3. *Structure of Themes, Example Quotes, and Number of Studies Contributing to Each Theme*

Sub Themes	Supporting Quotes and References	Number of Studies
Master Theme 1 – How do I know that someone is my friend?		8
I like the way they act and look	“Good sense of humour.” (Brackenbridge & Mackenzie, 2005)	2
We like doing things together	“It is someone you can do things with, like going swimming or going to the pictures.” (Bane et al., 2012)	7
We are similar	“Its hard to be friends if they ain’t got disability, they just don’t understand ...[Q]... don’t know, guess that’s why you stick to your friends that got disability.” (McVilly et al., 2006)	3
We can talk to each other	“You can talk to a friend ...[Q]... like you can’t talk to your mum or dad ...[Q]... friends listen to what you have to say and take it serious.” (McVilly et al., 2006)	4
We support each other	“You can ask them for help and they will always help” (McVilly et al., 2006)	5
How friendships make me feel	“Makes me feel better.” (Brackenridge & McKenzie, 2005)	4

Master Theme 2 – How do I know that someone is my boyfriend or girlfriend?		13
I like the way they act and look	"I like a girl that's kind and not selfish." (Kelly et al., 2009)	3
We like being together	"Mainly just being together, you know that counts, it doesn't matter if you have nothing, as long as you have each other, isn't that right!" (Lafferty et al., 2013)	7
How relationships make me feel	"It makes me feel special it makes me feel wanted you know it makes me feel as though someone does care about me." (Pestka & Wendt, 2014)	11
We support each other	"What she couldn't do I done for her and [what] I couldn't do, she done for me and we worked together." (Lafferty et al., 2013)	8
Expressing feelings in romantic ways	"I'll be her, like I told her, I'll be like her knight in shining armour no matter how we stand." (Wheeler, 2007)	7
Physical intimacy	"You can have each other to cuddle." (Yacoub & Hall, 2009)	12
Master Theme 3 – What helps and hinders relationships?		18
Living situation	"I had my room but not my privacy." (Yacoub & Hall, 2009)	5
Safety	"We sit down and kiss and that's it. What, nothing, I can't, I can't even walk through town with him...Frightened people will say [something]." (Rushbrooke et al., 2014)	10
Money and funding	"Well, I would like to get to go out a lot more. To get to know a lot more new friends... it's because of the funding of staffs. The money is not there for that". (Bane et al., 2012)	3
Transportation	"its hard when you got too far to travel ...[Q]... like mum has to drive and she's got lots of shopping to do and then I can't see my friends". (McVilly et al., 2006)	4
Services and programs	"Interviewer: Jenny, okay, okay. So tell me a bit more about her. Oliver: She's just a friend Interviewer: Yeah? Okay. So you see her at the day centre. Oliver: Yeah. Interviewer: And, where else? Oliver: That's all, at the day centre." (Mason et al., 2013)	7

Staff and family members	"My parents are a bit unfair about letting me out with my friends and stuff." (Bane et al., 2012)	11
My relationship is my business	"When I was going out with this fella (...) One staff didn't like it (...) he didn't want this person going out with me (...) But we still went out (...) – it's none of his business anyways (...) I still wanted to go out with him and I did." (Kelly et al., 2009)	4

How do I know that someone is my friend?

I like the way they act and look. Participants spoke about personality traits and physical characteristics that they liked and wanted in their friends. Personality traits included being social, kind, funny, and confident (Brackenridge & McKenzie, 2005; McVilly et al., 2006). While the personality traits they associated with unpopular people included being aggressive, bossy, loud, and mean (i.e., bullying) (Brackenridge & McKenzie, 2005; McVilly et al., 2006). An example of a physical characteristic that participants liked was “nice hair”; whereas, they indicated that a characteristic of unpopular people included “looking strange” (Brackenridge & McKenzie, 2005).

We like doing things together. Participants reported that they liked spending time and socializing with their friends and they stated that it was important to have fun doing activities together (Brackenridge & Mackenzie, 2005; McVilly et al., 2006). When defining a friend, one participant specified that it is “someone you can do activities with” (Bane et al., 2012). Some of the activities that were mentioned included going swimming, to pubs, to the movies, clubbing, and having meals together (Mason et al., 2013; Ward, Bosek, & Trimble, 2010). Some participants engaged in prolonged activities, such as going on vacations, with their friends (Mason et al., 2013).

We are similar. Participants thought it was important for friends to enjoy the same activities (McVilly et al., 2006). They tended not to like people who “need a lot of help”

(Brackenridge & McKenzie, 2005), indicating that they did not want friends who were lower functioning than themselves. Participants said that people with ID tend to be friends with others who have ID and it can be difficult to have friends who do not have disabilities (McVilly et al., 2006; The Money, Friends and Making Ends Meet Research Group, United Kingdom, 2012). The reasons they stated for this included wanting to have equality between friends and being able to relate to and communicate with each other (Mason et al., 2013; McVilly et al., 2006). Some participants also said it was hard to make friends because of their disabilities; for example, some people teased them about having a disability (Mason et al., 2013; McVilly et al., 2006).

We can talk to each other. Participants emphasized the importance of communication (McVilly et al., 2006). They discussed the meaningfulness of communication that can occur between friends and indicated that friends take what you say seriously (McVilly et al., 2006). Participants equated friendship with trust (Yacoub & Hall, 2009); some participants said that friends had to be truthful and be able to keep secrets (McVilly et al., 2006). Although communication seemed to be important within friendships, participants tended not to keep in contact when apart from each other (McVilly et al., 2006).

We support each other. Participants spoke about doing things for one another and helping each other with practical needs, such as fixing a light socket (McVilly et al., 2006; Yacoub & Hall, 2009). Furthermore, people who are always willing to help were considered “best friends” (McVilly et al., 2006). Participants also emphasized that friends provide emotional support (Yacoub & Hall, 2009). They said that friends know when they are sad (Brackenridge & McKenzie, 2005) and will be there for them (Bane et al., 2012). Participants also talked about

providing emotional support for their friends (Mason et al., 2013), although they noted that sometimes providing emotional support could be distressing (Mason et al., 2013).

How friendships make me feel. Participants tended to view their friendships positively (Mason, Timms, Hayburn, & Watters, 2013) and reported that friends made them feel better (Brackenridge & McKenzie, 2005). They also noted that friends provide support during life transitions, such as moving into a new home (Mason et al., 2013), and friends were able to help them feel less lonely (Walter-Brice, Cox, Priest, & Thompson, 2012). Participants reported that they missed their friends when they were apart from each other (Mason et al., 2013). Furthermore, they indicated that it could be upsetting when friendships ended (McVilly et al., 2006), indicating that participants wanted to maintain their friendships.

How do I know that someone is my boyfriend or girlfriend?

I like the way they act and look. Participants wanted significant others to be nice, kind, and not selfish (Kelly et al., 2009). They also reported liking partners' eyes, hair, and body types (Kelly et al., 2009; Ward et al., 2010). Participants indicated that it was difficult to form new relationships when people did not make an effort to do so (Rushbrooke et al., 2014).

We like being together. Participants reported that they engaged in activities with their friends, such as going to the movies and having meals together (Lafferty et al., 2013; Ward et al., 2010; Yau et al., 2009; Sullivan et al., 2013). They also talked about going on walks, to book stores and to the opera (Bane et al., 2012; Lafferty et al., 2013). Participants placed great importance on being in one another's company, regardless of the activity they were engaged in (Lafferty et al., 2013). Participants also expressed desires to get married and/or live together (Lafferty, McConkey, & Taggart, 2013; Wheeler, 2007; Yau et al., 2009). They talked about wanting to

engage in household duties together (Lafferty, McConkey, & Taggart, 2013). Some participants also wanted to raise children with their significant others (Lafferty, McConkey, & Taggart, 2013; Wheeler, 2007). Those participants who were married with children said they enjoyed the experience (Pestka & Wendt, 2014).

How relationships make me feel. Participants indicated that they knew someone was their partner based on their feelings (Ward, Bosek, Trimble, 2010). Participants stated that they enjoyed being in intimate relationships (Bane et al., 2012; Fitzgerald & Withers, 2013; Kelly, Crowley, & Hamilton, 2009) and the feeling of being in love (Yau, Ng, Lau, Chan, & Chan, 2009). Relationships helped increase independence and enhanced confidence (Lafferty et al., 2013). Reportedly, relationships also helped participants feel special, wanted, and cared for; they also provided a source of support and security (Kelly et al., 2009; Lafferty, McConkey, & Taggart, 2013; Pestka & Wendt, 2014; Rushbrooke, Murray, & Townsend, 2014; Yau et al., 2009). However, some participants indicated that positive feelings toward their significant others had decreased over time (Rushbrooke, Murray, & Townsend, 2014).

We support each other. Similar to friendships, participants discussed the practical and emotional support provided within their relationships. They talked about helping one another and wanting to be cared for (Rushbrooke et al., 2014; Wheeler, 2007; Yau et al., 2009). Participants discussed reciprocity within relationships; partners helped each other when one of them was in need (Lafferty et al., 2013). Throughout marriage, partners indicated that they helped each other with daily activities (Lafferty et al., 2013). Participants also talked about being kind and respectful (Kelly et al., 2009) and supporting each other through emotionally difficult experiences (Lafferty et al., 2013).

Expressing feelings in romantic ways. Participants talked about having romantic interactions with their significant others (Bane et al., 2012). They expressed feelings for one another, using phrases such as “knight in shining armour” (Wheeler, 2007). Participants also discussed romantic gestures made by others toward them (Kelly et al., 2009), and participants linked romance to physical intimacy (Rushbrooke et al., 2014). Furthermore, they described relationships in reference to romance and being in love (Yau et al., 2009). Romantic feelings were only discussed when talking about intimate relationships, not friendships, which indicates how feelings differ between these different types of relationships.

Physical intimacy: From holding hands to having sex. Physical intimacy was a common activity in intimate relationships. Participants reported that they held hands, cuddled, kissed, massaged, and had sexual intercourse with their partners (Bane et al., 2012; Fitzgerald & Withers, 2013; Kelly et al., 2009; Pestka & Wendt, 2014; Rushbrooke et al., 2014; Sullivan, Bowden, McKenzie, & Quayle, 2013; Yacoub & Hall, 2009; Yau et al., 2009). One reason stated for being in a relationship was to be physically intimate (Bane et al., 2012; Rushbrooke et al., 2014), and some saw this as confirmation of being in a relationship (Sullivan et al., 2013; Yau et al., 2009). Some participants indicated that they experienced varying levels of physical intimacy throughout the course of their relationships (Sullivan et al., 2013), and between different partners (Rushbrooke et al., 2014). Not all individuals found sexual experiences pleasurable (Fitzgerald & Withers, 2013). Some participants indicated that they engaged in limited or no sexual activity within their relationships (Lafferty et al., 2013). Overall, there was a large variety in the types of sexual activity participants engaged in with their significant others, and the importance placed on these acts.

What helps and hinders friendships and intimate relationships?

Living situation. Participants reported that living independently was associated with greater ability to see friends, girlfriends, and boyfriends (Bane et al., 2012). Some participants living in secure hospitals stated that they had very little time to see their friends (Yacoub & Hall, 2009). However, living situation was a bigger focus when discussing intimate relationships. Partners in relationships expressed desires to live closer together or move in together in order to have more contact (Bane et al., 2012; Lafferty et al., 2013). Partners who lived together reported spending time with each other on a regular basis (Ward et al., 2010) and were very happy with the situation (Yacoub & Hall, 2009). Participants who lived in supervised residential settings (e.g., group homes) or with their parents reported they did not have privacy (Yacoub & Hall, 2009).

Safety. Safety concerns limited participants' social lives. Some participants did not feel safe going out at night (McVilly et al., 2006), which could affect the ability for partners to spend time together (Wheeler, 2007). Some participants were aware of potential relationship risks, as they had previously had negative experiences, such as financial exploitation (Lafferty et al., 2013). Other individuals were afraid of what people would say about their intimate relationship and therefore would not go out in public (Rushbrooke et al., 2014). Within intimate relationships, participants discussed safety issues associated with financial exploitation, psychological abuse, physical abuse, and sexual abuse (Eastgate, Van Driel, Lennox, & Scheermeyer, 2011; Fitzgerald et al., 2011; Kelly et al., 2009; Lafferty, McConkey, & Taggart, 2013; Pestka & Wendt, 2014; Rushbrooke et al.; Sullivan; Walter-Brice et al., 2012; Ward et al., 2010).

Money and funding. The cost of funding enough staff to be able to accompany participants on social outings limited their ability to meet new people and maintain friendships

(Bane et al., 2012). Participants also indicated that having minimal finances and little control over their money restricted them from spending time with their significant others (Lafferty et al., 2012; Wheeler, 2007). Participants who lacked a stable income felt that they were unable to progress in their relationships and/or get married (Yau et al., 2009).

Transportation. Participants said that access to public transportation was important for maintaining friendships and intimate relationships (Bane et al., 2012). Some participants practiced using public transportation in order to feel comfortable travelling alone (Bane et al., 2012). Although public transportation could help participants make and keep friends, some participants were unable to use (McVilly et al., 2006), or did not have access to public transportation (Yacoub & Hall, 2009). Some participants required caregivers to drive them to meet with friends; thus, the availability of transportation sometimes depended on how much time and energy caregivers had, as well as the importance that caregivers placed on the participants seeing their friends (McVilly et al., 2006).

Services and programs. Services tended to provide opportunities to socialize and form strong friendships (Mason et al., 2013), as well as meet romantic partners (Kelly et al., 2009). Some friendships were only maintained because people saw each other on a regular basis at service agencies (Mason et al., 2013). Participants also said they made friends and maintained intimate relationships at work or school (McVilly et al., 2006; Ward et al., 2010). In general, attending services or daily program provided opportunities to meet new people and maintain relationships.

Staff and family members. Caregiver support and control, was a prominent focus when discussing what aids and hinders forming and maintaining relationships.

Emotional support and advice. Caregivers were an important support in developing and maintaining friendships and intimate relationship (Bane et al., 2012; Mason et al., 2013). Participants sought out caregivers for advice about relationships (Mason et al., 2013; Rushbrooke et al., 2014). Family members provided emotional support through difficult experiences, such as during a break-up (Bane et al., 2012). Caregivers could also be a good source of support during the development of relationships; however, some participants said their relationships with staff were more important than with other individuals who have ID, and they preferred to have one-on-one time with staff (Mason et al., 2013).

Restricted choice making. Although caregivers were seen as a source of support, participants indicated that they also restricted choice making within the participants' relationships. Participants did not always have control over their social lives (Wheeler, 2007). Some participants felt that caregivers were too restrictive, and that they did not recognize the importance of spending time with friends (Bane et al., 2012; McVilly et al., 2006).

Some caregivers and organizations held more positive views toward intimate sexual relationships (Eastgate, Van Driel, Lennox, & Scheermeyer, 2011; Kelly et al., 2009). However, participants tended to talk about the negative views of those who support them. Some said they were not allowed to have a boyfriend or a girlfriend and there were consequences if they maintained intimate relationships (Fitzgerald & Withers, 2013; Kelly et al., 2009; Rushbrooke et al., 2014; Yacoub & Hall, 2009). When participants did have intimate relationships, they reported that caregivers often placed restrictions on sexual activity (Fitzgerald & Withers, 2013; Sullivan et al., 2013; Wheeler, 2007; Yau et al., 2009). Reportedly, some caregivers encouraged cuddling and kissing, but not sexual intercourse (Fitzgerald & Withers, 2013), while others told

the participants that they could not get married (Mason et al., 2013). Participants suggested that caregivers thought they were vulnerable because they had a disability, which is why these restrictions were placed on them (Rushbrooke et al., 2014).

Lack of privacy. A few participants said that caregivers accompanied them on dates, which some people did not like (Kelly et al., 2009). Other participants said they wanted privacy so they could have conversations with their significant others; however, they noted that staff were often in the same vicinity, which made them uncomfortable (Rushbrooke et al., 2014). Participants living with parents also felt as though they did not have privacy (Yacoub & Hall, 2009).

Responses to caregivers' attitudes. In some instances, participants stated that they were teased by caregivers about having intimate relationships and they felt embarrassed about this (Rushbrooke et al., 2014). Others viewed their caregivers as being hostile, when discussing the participants' intimate relationships (Wheeler, 2007), and said that their caregivers did not trust them (Kelly et al., 2009). Some participants accepted caregivers' attitudes toward intimate relationships (Yau et al., 2009), but others viewed these as unfair (Yacoub & Hall, 2009), disagreed with their caregivers' decisions/opinions (Kelly et al., 2009), and said they should be able to make their own choices regarding relationships (National Institute for Intellectual Disability, 2009). Sometimes, it was unclear whether or not participants liked or disliked caregiver involvement, but they generally seemed to accept it.

Coping with difficult situations. This theme arose in relation to intimate relationships. A subset of participants talked about resisting pressure to end their relationships by keeping their romantic relationships and physical intimacy secret (Kelly et al., 2009; Rushbrooke et al., 2014).

However, some explicitly told their caregivers that they would do what they wanted (Rushbrooke et al., 2014). Participants also spoke about coping with relationship problems and regulating their emotions; for example, this was done by removing oneself from a stressful situation (Rushbrooke et al., 2014). If the participants did not want to involve caregivers they reported that they spoke to someone else who they felt comfortable with (Rushbrooke et al., 2014).

Discussion

Summary of Findings

Friendships and intimate relationships were important to individuals with ID and they made them feel happy. Participants tended to be friends with people who support them, they can trust, and have similar interests. They also discussed feeling cared for in their intimate relationships, engaging in physical intimacy, and experiencing romantic feelings for their partners. Persons with ID were aware of safety concerns (e.g. financial exploitation, psychological and physical abuse) when exercising autonomy and choice-making within interpersonal relationships. However, they desired more independence. It was also evident that paid and unpaid caregivers played a major role in the formation and maintenance of interpersonal relationships. They provided support and guidance for individuals with ID in difficult interpersonal situations. They also drove people to their social outings. In contrast, persons with ID also reported that caregivers limited their interactions with friends or intimate partners. They sometimes overtly discouraged persons with ID from having intimate relationships, or close supervision limited opportunities for participants to have personal conversations with friends.

Contribution to the Current Knowledge

Some of the themes identified through this review are similar to what has been found for individuals without ID. Not surprisingly, and akin to adults without ID, many persons with ID value friendships and intimate relationships (Fraley & Davis, 1997). Research studying those with and without ID has also found that friends tend to mutually rely on one another (Bukowski, Motzoi, & Meyer, 2009; Knox & Hickson, 2001; Salmon, 2013; Weafer, 2010). Another common finding for persons with ID and those without, is that paid caregivers can help relationship development because the more frequently people see each other, the more likely they are to be friends (Healy et al., 2009; Löfgren-Mårtenson, 2004; Sprecher, 2013). This result was also found in research on elderly adults; senior centers staff help facilitate social contact (Aday et al, 2006). Although there are common findings related to relationship development and maintenance for individuals with and without ID, some experiences seem to be specific to those with ID.

Adults with ID often desire more close interpersonal relationships and want to spend more time with friends and romantic partners (Collins & Madsen, 2006; Cummins & Lau, 2003; Healy et al., 2009; Knox & Hickson, 2001). Whereas adults without ID tend to be satisfied with the amount of time they spend with their friends and significant others (Collins & Laursen, 2004). Although meaningful friendships can and do occur between those with ID and those who do not have ID (Pottie, 2004; Rossetti, 2011), people with ID tend to most easily connect with those who have similar levels of functioning and comparable experiences related to having a disability (Cummins & Lau, 2003; Knox & Hickson, 2001; Salmon, 2013).

Many discuss the development of friendships and intimate relationships throughout childhood and adolescence (e.g., Brown, Feiring, & Furman, 1999; Connolly & Coldberg, 1999). For example, in Brown's theory focusing on the development of heterosexual relationships, Brown (1999) explains that children first socialize in sex-segregated groups, and adolescents spend more time with the opposite sex and begin dating. Ultimately, relationships intensify and involve more emotional investment and sexual activity. In contrast, the current findings suggest that persons with ID do not experience this progression from friendships to intimate relationships and sexual involvement. They might not have comparable opportunities to experience the developmental process that has been described for those without ID, from childhood friendships to adult emotional and sexual relationships. However, individuals with ID do report experiencing different types of attraction as proposed by Reeder (2000): physical, romantic, and platonic. For example, participants talked about individuals with whom they were sexually involved with, yet were not in an intimate relationship with. Some participants also mentioned that they were in or had been involved in romantic relationships, during which they were not sexually involved with their partners. The findings from this review suggest that although their relationships may not develop in the same way, persons with ID likely experience the same types of attraction as individuals without ID.

This review highlights key external factors that could be modified to improve the experiences of those with ID, such as funding for individuals with ID and access to public transportation. Other important external factors which affect the abilities of individuals with ID to form and maintain interpersonal relationships are their living situations and amount of privacy they are given. Some individuals with ID view their lack of privacy as unfair and think restricted

independence could lead to unsafe practices (Healy et al., 2009; Hollomotz, 2009). Lack of privacy can also inhibit people with ID from forming closer relationships (Healy et al., 2009; Hollomotz, 2009). Caregivers may restrict their independence because individuals with ID are at high risk of physical and sexual abuse, and exploitation (Bryen, Carey, & Frantz, 2003). There is clearly a need to balance protection of persons with ID from harm, while promoting choice and autonomy within relationships (Knight, 2013; Saaltink, MacKinnon, Owen, & Tardif-Williams, 2012). In this review, participants tended to advocate for their rights and freedom to make their own choices, however other literature on young adults with ID indicates that they often do not question caregivers' decisions (Löfgren-Mårtenson, 2004). Studies focusing on caregivers' perspectives support some of the views expressed by the adults with ID in the studies we reviewed; caregivers thought persons with ID did not know what to do in relationships (Healy et al., 2009; Hollomotz, 2009), and that they would be unsafe (Löfgren-Mårtenson, 2004).

Similarly, other studies have found that caregivers tended to control intimate relationships and overt sexual activity (Hollomotz, 2009; Simpson, Lafferty, & McConkey, 2006), rather than friendships (Evans et al., 2009). This is consistent with the findings from this review; participants tended to speak more about restrictions being placed on intimate relationships compared to friendships. Parents of persons with ID tend to have more conservative views regarding their children's sexuality than those of staff (Cuskelly & Bryde, 2004), yet institutional policies can affect staff behaviour. Some staff have expressed feelings of being under pressure to inhibit sexual activities (Simpson et al., 2006), however, others have indicated that they ignore institutional rules and allow service-users to spend time in private with significant others (Hollomotz, 2009). Interestingly, there is minimal research that studies if and how parents directly influence adult relationships among those without ID; this body of research tends to

focus on how parent-child attachments affect future relationships, rather than looking at how parents' current behaviours affect current relationships (Sherman, de Vries, & Lansford, 2000).

Limitations

A limitation of this review is related to the presentation of results in the original studies. Due to the wide variation between studies in the reporting of participants' ages, levels of functioning, and living situations, it was not possible to meaningfully compare and contrast the experiences between individuals from different age groups or with different levels of functioning. Interpersonal relationship experiences can vary widely between individuals, and this was evident from our findings. For example, some participants in the original studies had engaged in sexual intercourse with multiple partners, while others had never engaged in sexual activity. Moving forward, studies should provide consistent, detailed descriptions of their samples, to allow meaningful conclusions to be drawn, about how experiences may differ between subsets of the population. Detailed reporting of ages, levels of functioning, and living situations would help researchers better understand how experiences differ between subsets of individuals with ID.

Due to the nature of the included studies, participants were able to verbally communicate during group discussions or individual interviews. Additionally, it was noted that many participants lived independently (i.e., alone, with spouses and/or children, or with friends), indicating that they do not have many support needs. The findings from this review may not be relevant to individuals who are unable to live independently and/or require support to communicate. This is especially important to remember when thinking about factors that inhibit the development and maintenance of relationships for individuals with ID. For example, the

participants in the included studies likely do not require as much supervision as those who have more support needs; however, caregivers may not recognize these differences, and consequently, they may unnecessarily restrict the relationships of individuals who require less support.

Although focusing on the perspectives of individuals with ID is very important and useful to understanding their unique experiences, it would also be beneficial to integrate these findings with research that focuses on caregiver perspectives. As mentioned previously, caregivers can provide insight into the difficulties related to increasing the independence of individuals with ID.

The majority of studies did not include the perspectives of those people whom participants identified as friends or partners. Therefore, when participants discussed specific relationships, it is often not clear if these friends or partners would consider the relationship reciprocal. Engaging in reciprocal relationships helps individuals feel valued, respected, and connected to others (Mahar, Cobigo, & Stuart, 2013), and these feelings are associated with mental and physical wellbeing (Kersh, Corona, & Siperstein, 2013). It would be beneficial to know if those friends or partners that the participants identified, perceive the relationship to be reciprocal, and if so, what aspects of the relationship do both parties view as important contributors to reciprocity. This information would allow for a more thorough understanding of how reciprocal relationships contribute to wellbeing for individuals with ID.

Another limitation is related to the generalizability of the results. The majority of the studies in this review did not include participants over the age of 65 years. Therefore, the results may not be relevant to older adults with ID. Likely because only English studies were included, all but one study (Yau et al., 2009) were conducted in western, English speaking, cultures (North

America, the United Kingdom, Ireland, and Australia). Values and social norms toward relationships may differ in other cultures (Dion & Dion, 1996). However, Yau and colleagues (2009), who conducted research in Hong Kong, had coherent results with the other reviewed studies. Future research should assess how relationship conceptualizations, barriers, and supports differ cross-culturally. Although there were approximately equal amounts of male and female participants, more studies that explored intimate relationship experiences (especially focusing on domestic violence) included only female participants. Thus, the findings related to these experiences may be more applicable to females with ID. Additionally, there is a focus on heterosexual relationships in the studies included in this review. Therefore, most of the findings regarding intimate relationships may be more applicable to those who identify as heterosexual. Overall, the findings in this review are most relevant for young to middle aged adults with ID who live in western, English speaking cultures.

Implications and Future Directions

Caregivers of persons with ID want to know how to better support relationships for these individuals (Evans et al., 2009). Additionally, staff have indicated that explicit policies and guidelines, related to sexuality and relationships, are needed to help them respect the rights, needs, and desires of individuals with ID, while at the same time, addressing their concerns regarding safety and protection from harm for those with ID (Simpson et al., 2006). Caregivers should be encouraged to shift their roles from unnecessary monitoring to providing opportunities for meeting people in different contexts, maintaining regular contact between friends, and providing privacy.

There is a need to evaluate and translate into practice the existing evidence on how to support friendships among individuals with ID, to enhance the support provided by caregivers. Research findings cannot affect change in practices and policies without translating the current body of knowledge into practice (Straus, 2011). The existing evidence on interventions and strategies for supporting friendships and romantic relationships for individuals with ID needs to be synthesized, evaluated, and translated to knowledge users. Then, staff and family caregivers will be better equipped to implement empirically supported strategies to more effectively support friendships, thereby enhancing the wellbeing of individuals with ID.

There are a number of potential strategies to better support the interpersonal relationships of individuals with ID. For example, persons with ID need to be aware of their rights related to freedom of choice surrounding interpersonal relationships (Rushbrooke et al., 2014). They also need to be educated on how to be self-advocates (Rushbrooke et al., 2014; Yacoub & Hall, 2009). To foster independence, persons with ID need to be aware of the potential risks involved in interpersonal relationships (e.g. exploitation, emotional and physical abuse). Educating persons with ID on safety tips and who they can talk to about their relationships, if they have questions or concerns, may allow both persons with ID and their caregivers to feel more comfortable with new situations surrounding relationships. Sexual education, which discusses the positive and negative aspects of sexuality, sexual interactions, and romantic relationships could help reduce safety concerns and promote fulfilling intimate relationships. In fact, sexual education has allowed adults with ID to gain independence and make choices for themselves (Dukes & McGuire, 2009). Programs could also include education on strategies for coping with emotionally difficult situations and how to communicate with others. Education on how to build relationships and manage conflict (Runnion & Wolfer, 2004)

would also be useful in empowering adults with ID to make their own decisions within relationships.

Policies guiding services for persons with ID must incorporate their preferences in regards to interpersonal relationships. Policies tend to place a focus on community integration, in an attempt to contest the social exclusion of persons with ID. Although this appears necessary, policies should also promote relationships between people who do have disabilities, as these relationships seem to be very important to these individuals. Many people with ID connect more easily with others who have ID, therefore to enhance feelings of belonging and social connectedness, promoting reciprocal relationships with others who have ID would be beneficial (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Cummins & Lau, 2003; Western, McCrea & Stimson, 2007). Regardless of whether or not friends and partners have ID, it is important to promote reciprocal relationships to foster a sense of belonging (Mahar, Cobigo, & Stuart, 2013; Western, McCrea & Stimson, 2007). In addition, social policies tend to focus on the protection of individuals with ID who are considered to be vulnerable to harm (Fistein, Holland, Clare, & Gunn, 2009). Current policies should promote the right to make one's own choices, in the context of relationships, to truly enhance social inclusion among this population (Barron, 2001).

Conclusion

Social support and meaningful interpersonal relationships are important contributors to mental and physical health (Hefner & Eisenberg, 2009; Marmot & Wilkinson, 2005). Persons with ID are often socially isolated; they are less likely to receive emotional support, have smaller social networks, and experience more feelings of loneliness (Bhaumik et al., 2008; Haverkamp et al., 2004; Lippold & Burns, 2009). Thus, it is imperative that these individuals are given opportunities to build reciprocal relationships to enhance their quality of life and social inclusion.

Staff and family caregivers have indicated that they need more training to support the relationships of persons with ID (Evans et al., 2009). Understanding how people with ID describe relationships, and being aware of the factors that support and impede relationships will aid stakeholders in developing training, policies, programs, and services. However, knowledge translation of research that focuses on strategies aimed at supporting relationships is crucial to affect change in applied settings and improve quality life for persons with ID.

References

- Arias, B., Ovejero, A., & Morentin, R. (2009). Love and emotional well-being in people with intellectual disabilities. *The Spanish Journal of Psychology*, 12(01), 204-216.
- Bane, G., Dooher, M., Flaherty, J., Mahon, A., Donagh, P. M., Wolfe, M., . . . Shannon, S. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities*, 40(2), 109-122.
- Barron, K. (2001). Autonomy in everyday life, for whom?. *Disability & Society*, 16(3), 431-447.
- Bhaumik, S., Tyrer, F., McGrother, C., & Ganghadaran, S. (2008). Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 52(11), 986-995.
- Brackenridge, R., & McKenzie, K. (2005). The friendships of people with a learning disability. *Learning Disability Practice*, 8(5), 12-17.
- Brown, B. B., Feiring, C. and Furman, W. (1999). Missing the love boat: Why researchers have shied away from adolescent romance. In *The Development of Romantic Relationships in Adolescence*, W. Furman et al. (Eds). Cambridge, U.K.: Cambridge University Press.
- Bryen, D. N., Carey, A., & Frantz, B. (2003). Ending the silence: Adults who use augmentative Communication and their Experiences as Victims of Crimes. *Augmentative and Alternative Communication*, 19(2), 125-134.

- Bukowski, W. M., Motzoi, C., & Meyer, F. (2009). Friendship as process, function, and outcome. *Handbook of Peer Interactions, Relationships, and Groups*, 217-231.
- Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative research. *Sage Publications Ltd, London*.
- Cobigo, V., Ouellette-Kuntz, H., Lysaght, R., & Martin, L. (2012). Shifting our conceptualization of social inclusion. *Stigma research and action*, 2(2).
- Collins, W. A., & Laursen, B. (2004). Parent-adolescent relationships and influence. In R. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology* (pp. 331–362). New York: Wiley.
- Collins, W. A., & Madsen, S. D. (2006). Personal relationships in adolescence and early adulthood. In A. L. Vangelisti & D. Perlman (Eds.), *The Cambridge handbook of personal relationships* (pp. 191–209). New York: Cambridge University Press.
- Connolly, J. and Goldberg, A. (1999). Romantic relationships in adolescence. The role of friends and peers in their emergence and development. In *The Development of Romantic Relationships in Adolescence*, W. Furman et al. (Eds). Cambridge, U.K.: Cambridge University Press.
- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130.

- Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(2), 145-157.
- Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual and Developmental Disability*, 29(3), 255-264.
- Department of Health (2007) *Valuing people now: From progress to transformation – a consultation on the next three years of learning disability policy*. London, Department of Health.
- Dion, K. K., & Dion, K. L. (1996). Cultural perspectives on romantic love. *Personal Relationships*, 3(1), 5-17.
- Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53(8), 727-734.
- Eastgate, G., Van Driel, M. L., Lennox, N., & Scheermeyer, E. (2011). Women with intellectual disabilities: A study of sexuality, sexual abuse and protection skills. *Australian Family Physician*, 40(4), 226.
- Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in northern England. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 191-197.

- Evans, D. S., McGuire, B. E., Healy, E., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research*, 53(11), 913-921.
- Fiori, K. L., Antonucci, T. C., & Cortina, K. S. (2006). Social network typologies and mental health among older adults. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 61(1), P25-32.
- Fistein, E., Holland, A., Clare, I., & Gunn, M. (2009) A comparison of mental health legislation from diverse commonwealth jurisdictions. *International Journal of Law and Psychiatry*, 32, 147–155.
- Fitzgerald, C., & Withers, P. (2013). ‘I don’t know what a proper woman means’: What women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities*, 41(1), 5-12.
- Fraley, R., & Davis, K. E. (1997). Attachment formation and transfer in young adults’ close friendships and romantic relationships. *Personal Relationships*, 4, 131–144.
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192-199.
- Glidden, L. M., Bamberger, K. T., Draheim, A. R., & Kersh, J. (2011). Parent and athlete perceptions of Special Olympics participation: Utility and danger of proxy responding. *Intellectual and Developmental Disabilities*, 49(1), 37-45.

- Havercamp, S. M., Scandlin, D., & Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Reports*, 119(4), 418-426.
- Healy, E., McGuire, B., Evans, D., & Carley, S. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*, 53(11), 905-912.
- Hefner, J., & Eisenberg, D. (2009). Social support and mental health among college students. *American Journal of Orthopsychiatry*, 79(4), 491.
- Hollomotz, A. (2009). 'May we please have sex tonight?' – People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, 37(2), 91-97.
- Inclusive Research Network. (2010). *Relationships and supports study: People with intellectual disabilities in Ireland*. Dublin: National Institute for Intellectual Disability Ireland; Galway: National Federation of Voluntary Bodies.
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban Health*, 78(3), 458-467.
- Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: 'It'd be nice to be kind of trusted'. *British Journal of Learning Disabilities*, 37(4), 308-315.

- Kersh, J., Corona, L., & Siperstein, G. (2013). Social well-being and friendship of people with intellectual disability. *The Oxford handbook of positive psychology and disability*, 60-81.
- Knight, K. (2013). The changing face of the 'good mother': Trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, 28(5), 660-673.
- Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 276-291.
- Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, 28(8), 1074-1088.
- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53(5), 463-473.
- Löfgren-Mårtenson, L. (2004). "May I?" About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability*, 22(3), 197-207.
- Lunsky, Y., & Benson, B. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research*, 45(2), 106-114.

- Mactavish, J. B., Mahon, M. J., & Lutfiyya, Z. M. (2000). "I can speak for myself": Involving individuals with intellectual disabilities as research participants. *Mental Retardation*, 38(3), 216-227.
- Mahar, A. L., Cobigo, V., & Stuart, H. (2013). Conceptualizing belonging. *Disability and rehabilitation*, 35(12), 1026-1032.
- Marmot, M., & Wilkinson, R. (2005). *Social determinants of health*. Oxford University Press.
- Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities*, 26(2), 108-118.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & BurtonSmith, R. M. (2006). Self-advocates have the last say on friendship. *Disability & Society*, 21(7), 693-708.
- Miller, B. C., & Benson, B. (1999). Romantic and sexual relationship development during adolescence. *The development of romantic relationships in adolescence*, 99-121.
- National Institute for Intellectual Disability. (2009). *All we want to say: Life in Ireland for people with intellectual disabilities*. Dublin: Trinity College.
- Nosek, M. A., Howland, C. A. & Young, M. E. (1997). Abuse of women with disabilities: Policy implications. *Journal of Disability Policy Studies*, 8, 157 – 175.
- Pestka, K., & Wendt, S. (2014). Belonging: Women living with intellectual disabilities and experiences of domestic violence. *Disability & Society*, 29(7), 1031-1045.

- Pottie, C. & S., J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation*, 42(1), 55-66.
- Reeder, H. M. (2000). 'I like you... as a friend': The role of attraction in cross-sex friendship. *Journal of Social and Personal Relationships*, 17(3), 329-348.
- Rossetti, Z. S. (2011). "That's how we do it": Friendship work between high school students with and without autism or developmental disability. *Research & Practice for Persons with Severe Disabilities*, 36(1), 23-33.
- Runnion, V. M., & Wolfer, T. A. (2004). Relationship disruption in adults with cognitive disabilities. *Families in Society: The Journal of Contemporary Social Services*, 85(2), 205-213.
- Rushbrooke, E., Murray, C., & Townsend, S. (2014). The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 27(6), 531-541.
- Saaltink, R., MacKinnon, G., Owen, F., & Tardif-Williams, C. (2012). Protection, participation and protection through participation: Young people with intellectual disabilities and decision making in the family context. *Journal of Intellectual Disability Research*, 56(11), 1076-1086.
- Salmon, N. (2013). 'We just stick together': How disabled teens negotiate stigma to create lasting friendship. *Journal of Intellectual Disability Research*, 57(4), 347-358.

- Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., ... & Shogren, K. A. (2010). Intellectual disability: Definition, classification, and systems of supports. Washington, DC: American Association on Intellectual and Developmental Disabilities.
- Scottish Executive. (2000). The Same as You? A Review of Services for People with Learning Disabilities. Edinburgh, Scotland: Her Majesty's Stationary Office.
- Services and Supports to promote the Inclusion of Persons with Developmental Disabilities Act (2008, c. 14). Retrieved from the Government of Ontario website:
<http://www.ontario.ca/laws/statute/08s14>
- Sherman, A. M., De Vries, B., & Lansford, J. E. (2000). Friendship in childhood and adulthood: Lessons across the life span. *The International Journal of Aging and Human Development*, 51(1), 31-51.
- Simpson A, Lafferty A, & McConkey R. (2006). *Out of the shadows: A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland*. Belfast: FPA.
- Singh, J. (2013). Critical appraisal skills programme. *Journal of Pharmacology and Pharmacotherapeutics*, 4(1), 76.
- Sprecher, S. (2013). *Handbook of relationship initiation*. Routledge.
- Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *Canadian Medical Association Journal*, 181(3-4), 165-168.

- Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2013). 'Touching people in relationships': A qualitative study of close relationships for people with an intellectual disability. *Journal of Clinical Nursing*, 22(23-24), 3456-3466.
- Taylor, J., Lambeth, P. F., & Lives, S. O. (2007). *We are not stupid*. People First Lambeth/Shaping Our Lives.
- The Money, Friends and Making Ends Meet Research Group, United Kingdom. (2012). Having friends-they help you when you are stuck. From money, friends and making ends meet research group. *British Journal of Learning Disabilities*, 40(2), 128-133.
- Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45). doi:10.1186/1471-2288-8-45
- United Nations. (2006). UN Convention on the Right of Persons with Disabilities. Available at: <http://www.un.org/disabilities/convention/conventionfull.shtml>
- Walter-Brice, A., Cox, R., Priest, H., & Thompson, F. (2012). What do women with learning disabilities say about their experiences of domestic abuse within the context of their intimate partner relationships? *Disability & Society*, 27(4), 503-517.
- Ward, K. M., Bosek, R. L., & Trimble, E. L. (2010). Romantic relationships and interpersonal violence among adults with developmental disabilities. *Intellectual and Developmental Disabilities*, 48(2), 89-98.

- Weafer, J. A. (2010). Chapter two – The views and experiences of people with intellectual disabilities. In *Independent and community living: Focus group consultation report*.
Obtained from: <http://nda.ie/Publications/Social-Community/Independent-and-Community-Living-Focus-Group-Consultation-Report/Chapter-Two-The-views-and-experiences-of-people-with-intellectual-disabilities/>
- Western, J., McCrea, R., & Stimson, R. (2007). Quality of life and social inclusion. *International Review of Sociology—Revue Internationale de Sociologie*, 17(3), 525-537.
- Wheeler, P. (2007). 'I count myself as normal, well, not normal, but normal enough. Men with learning disabilities tell their stories about sexuality and sexual identity. *Tizard Learning Disability Review*, 12(1), 16-27.
- Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: A qualitative study. *British Journal of Learning Disabilities*, 37(1), 5-11.
- Yau, M. K., Ng, G. S., Lau, D. Y., Chan, K. S., & Chan, J. S. (2009). Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context. *British Journal of Developmental Disabilities*, 55(109), 97-108.

Chapter 3: A Review of Strategies to Support Friendships for Adults with Intellectual Disabilities

Fulford, C., Ressel, M., & Cobigo, V. (2018). *A Review of Strategies to Support Friendships for Adults with Intellectual and Developmental Disabilities*. Unpublished Manuscript.

Contribution

Author Contributions

Casey Fulford, the primary author, reviewed the systematic literature search decisions made by Madelaine Ressel, conducted quality assessments and data analysis, and wrote a significant portion of the paper content.

Madelaine Ressel, the secondary author, conducted the systematic literature review, conducted quality assessments, and contributed to the content of the paper.

Dr. Virginie Cobigo, the supervising author, met with Ms. Fulford frequently to discuss the research questions, search strategy, and data analysis. Throughout the process, Dr. Cobigo provided guidance and recommendations regarding article content and edited the full paper.

Funding

There was no funding provided for the completion of this paper

Preamble

For individuals to receive services that are informed by research, knowledge mobilization (KM) must occur (Graham et al., 2006; Graham, Tetroe, & KT Theories Research Group, 2007). Incorporating different types of knowledge to improve services for adults with intellectual disabilities (ID) and engaging in evidence-based decision-making within community-based organizations has the potential to change outcomes for this population. Although much important and pertinent research is conducted relating to individuals with ID, there is a paucity of research that examines the process of KM to enhance outcomes for people with ID (Martin, Shooshtari, Temple, & Yu, 2010; Shooshtari et al., 2014). Additionally, limited research has been conducted related to KM in community-based settings (Kothari & Armstrong, 2011), and we have found none that focuses on supporting friendships for adults with ID. If service-providers are to effectively support the friendships of individuals with ID, it is crucial that we understand how to engage in the KM process with community-based organizations.

This paper consists of a systematic literature review that identifies existing friendship supports for adults with ID. This literature review focused on strategies that included individuals who were 16 years of age and older, because it was used to inform the KM process in a community-based service organization that provides services to adults who are 16 years of age and older. The first literature review [Chapter 2] search criteria included individuals who were as young as 14 years of age, because at the time that review was conducted we did not yet know the age of the service-users with whom we would be working, and had been considering including high school students. However, we do not view the differing age ranges as a cause for concern,

given that the first literature review [Chapter 2] included only one study (out of 18 studies) that had participants under the age of 18 years old.

Abstract

Despite the priority placed on social inclusion in policies and practices, individuals with intellectual disabilities (ID) have limited opportunities to develop and maintain meaningful friendships; contributing to poorer mental, physical, and quality of life outcomes. Community-based organizations play a critical role in friendships for adults with ID. This systematic review assessed and summarized the existing research on strategies to support friendships of adults with ID, with the aim of informing the knowledge mobilization (KM) process within community-based organizations. The final five strategies examined included 1) volunteers facilitating interactions between individuals with ID; 2) college volunteers befriending individuals with ID; 3) weekly social goal workshops; 4) inclusive sports teams to foster friendships; and 5) systematically planned activities to support social interactions. Overall the level of evidence was low. However, all strategies resulted in at least one positive short-term social outcome. Findings suggest a paucity of high quality research on programs designed to support friendships for individuals with ID, and highlight the need for systematic research evaluating friendship support programs in the community context. The findings have the potential to inform KM in community-based settings, which can lead to improved supports for adults with ID, and consequently may improve the social lives of this population.

Introduction

Adults with intellectual disabilities (ID) consistently report that making friends and participating in activities with friends are among their greatest desires (Brackenridge & McKenzie, 2005; Cummins & Lau, 2003; Emerson & McVilly, 2004; Knox & Hickson, 2001; Mason, Timms, Hayburn, & Watters, 2013; Weafer, 2010). Although many people with ID are physically integrated in their communities, most remain socially isolated with very few friends (Abbott & McConkey, 2006; Cobigo, Ouellette-Kuntz, & Lysaght, 2012; Lippold & Burns, 2009; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006). Feelings of loneliness and low social support can aggravate pre-existing problems with emotional, physical, behavioral, and cognitive problems for individuals with ID (Gilmore & Cuskelly, 2014; Lunskey & Benson, 2001; McVilly et al., 2006). Despite the priority placed on social inclusion in recent policy and practice, people with ID continue to have limited opportunities to develop and maintain meaningful friendships (Emerson & McVilly, 2004; Lippold & Burns, 2009).

Even though community-based organizations can provide opportunities and support to socialize, implementing effective friendship interventions continues to be a major challenge (Mason et al., 2013). Barriers to successful support include lack of training, resources, and guidance provided to service-providers (Abbott & McConkey, 2006; Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014; McConkey & Collins, 2010). In addition, staff must follow organizational policies and manage their own and caregivers' concerns regarding service-users' safety, which may further limit opportunities to engage in meaningful relationships (Asselt-Goverts et al., 2014; Finlay, Walton, & Antaki, 2008; Weafer, 2010). It can also be difficult to develop strategies that will meet the needs of all service-users, because individuals with ID are a heterogeneous group (McVilly et al., 2006). This being said, it is important for friendship

support strategies to be flexible enough to align with service-users' individual preferences and needs. As a result, community-based organizations that support individuals with ID encounter many obstacles when trying to support friendships of individuals with ID.

To our knowledge, there are no existing reviews assessing research on strategies for supporting friendships of adults with ID. Previously, a review highlighting social participation interventions was published (Howarth, Morris, Newlin, & Webber, 2016), and the included studies focused primarily on community integration rather than supporting friendships. Because friendships do not necessarily develop from community participation (Abbott & McConkey, 2006; Cobigo et al., 2012; Lippold & Burns, 2009; McVilly et al., 2006a), it is important to understand how friendship support strategies differ from social participation interventions.

The aim of this literature review was to inform the knowledge mobilization (KM) process for supporting friendships of individuals with ID, in a community-based setting. This was done by assessing and summarizing the research that is currently available on strategies to support friendships for individuals with ID. The findings from this review can be useful for service-providers who are interested in implementing strategies intended to facilitate friendships.

Method

We conducted a systematic review to appraise and summarize relevant research on strategies to support friendships for individuals with ID. Conducting a systematic review includes developing a thorough search strategy, selecting all relevant articles, evaluating the research, and integrating and comparing the findings (Uman, 2011).

Search Strategy

Primary research studies, written in English, and published between January 1980 and December 2016, were included in the review. We selected a starting date of 1980 because de-

institutionalization of individuals with ID began being promoted by the Canadian Federal Government at the beginning of the 1980s (Lemay, 2009). This led to many more individuals with ID living in the community and the need for strategies to support community inclusion and relationships (Lemay, 2009). We included both quantitative and qualitative studies evaluating strategies, programs, or interventions for supporting friendships of individuals with ID were included. In addition, studies needed to 1) contain a description of and evaluation of outcomes for the strategy under consideration, and 2) involve individuals with ID who are predominantly over the age of 16. (Some articles contained individuals as young as 12 years of age. However, we deemed them relevant because the included strategies were geared towards young and older adults, as well. The majority of participants with ID included in these studies over the age of 16 years.) Articles included in the review were identified through a literature search and subsequent quality assessment. The literature search included three phases: 1) a systematic online database literature search, 2) a hand search, and 3) a grey literature search.

For the online database search strategy, a librarian was consulted. First, we conducted a keyword search consisting of (*"intellectual disabilit*" OR "developmental disabilit*" OR "learning disabilit*" OR "intellectual and developmental disabilit*" OR "mental retard*"*) AND (*"social relationship*" OR "interpersonal relationship*" OR "friend*"*). The following databases were searched: PsycINFO, MedLine, ERIC, and Web of Science. Studies were assessed for inclusion through a title review, an abstract review, and a full article review. For the hand search, the references cited in the resultant articles were scanned. These studies were also assessed for inclusion through a title review, an abstract review, and a full article review. For the grey literature search, we conducted Google searches using the same combinations of terms from the database search. The titles from the first four pages of the search results were read and when

deemed relevant, the full studies were read to determine if they met all inclusion criteria. All corresponding authors of included studies were contacted to obtain missing information about the strategies.

Quality Assessment

The Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011) was designed to evaluate quantitative, qualitative, and mixed-methods research. In the current review, the MMAT was used to assess the quality of all included studies. (See Appendix B to view the MMAT.) The primary and supervising authors independently conducted quality assessments on each included article. We then compared responses and when there were disagreements, we reviewed the content of the article together. Then, if needed we further discussed our rationales and came to a consensus based on these discussions. Each article was scored as either zero or one on initial screening questions. Articles were scored as zero if the criterion in the question was not met or the relationship to the criterion could not be determined. Articles received a score of one if the criterion was met. Studies were excluded if they received zeros on both screening questions. Remaining articles then received a total score based on the criteria relevant to each type of study. The total scores were determined by calculating the percentage of criteria that were fulfilled (i.e., if two out of four criteria were fulfilled, the final score would be 50%). Total scores for qualitative studies were calculated using scores for criteria pertaining to qualitative methods. Total scores for quantitative studies were calculated using scores for criteria specific to the type of quantitative method (i.e., randomized control, non-randomized, descriptive). Total scores for mixed-methods studies were determined by using the scores for criteria pertaining to qualitative methods, the specific type of quantitative methods used, and mixed-methods criteria. Only articles receiving a total score of 50% or above were included in the review.

Appraisal of Evidence

The included articles were assigned a level of evidence according to the Hierarchy of Study Designs to Assess the Effects of Interventions (University of York & NHS Centre for Reviews and Dissemination, 2009). The level of evidence indicates the strength of the results found in a research study. There are three levels of evidence (1, 2, or 3) that are determined based on the methods used in a study. Level 1 refers to randomized controlled trials (participants are randomly assigned to groups), level 2 refers to quasi-experimental studies (i.e., participants are allocated to groups using other methods than random assignment), and level 3 refers to observational studies (natural variations amongst participants lead to participant groupings). When comparing the levels assigned to different studies, lower numbers indicate stronger results (i.e., there is a higher likelihood that the outcomes described in the study are due to the strategy that was implemented rather than other factors).

Data Extraction and Analysis

The studies that met all inclusion criteria and passed the quality assessment (50% or above) were imported into QSR NVivo (version 10). All written text was included in the analysis. The data analysis was informed by guidelines developed by Miles, Huberman, and Saldana (2013) for qualitative data analysis. We reviewed each paper several times and developed a list of deductive codes to meaningfully compare the different strategies. We then applied this coding structure to the data and revised it as necessary, based on the content included in each article. Information was ultimately extracted and integrated in terms of the following overarching categories: 1) the strategy description, 2) participant characteristics, and 3) the results of the study. Once all data was coded, summaries of the raw data (for each category and strategy) were written and organized into a matrix to allow for comparison between the

different strategies for supporting friendships of individuals with ID. The matrix was based off a Role Matrix, as described by Miles, Huberman, and Saldana (2013).

A senior researcher was consulted throughout data analysis; she provided guidance on the methods used and gave feedback at each step of data analysis. After the researchers established a coding structure, the first author applied it to all raw data and second author coded 25% of the data to determine inter-rater reliability ($\kappa = .82$). The summaries of the raw data, included in the matrix, were reviewed by both coders to enhance their validity and ensure they accurately reflected the raw data.

Findings

See Figure 3.1 for a breakdown of the database search findings and quality assessment findings. Twelve articles from the online database search met inclusion criteria and were assessed for quality. See Figure 3.2 for a breakdown of the hand search findings. No articles from the hand search or grey literature search met inclusion criteria. After conducting a quality assessment by applying the MMAT criteria, five articles remained. See Table 3.1 for the quality assessment details for the included studies.

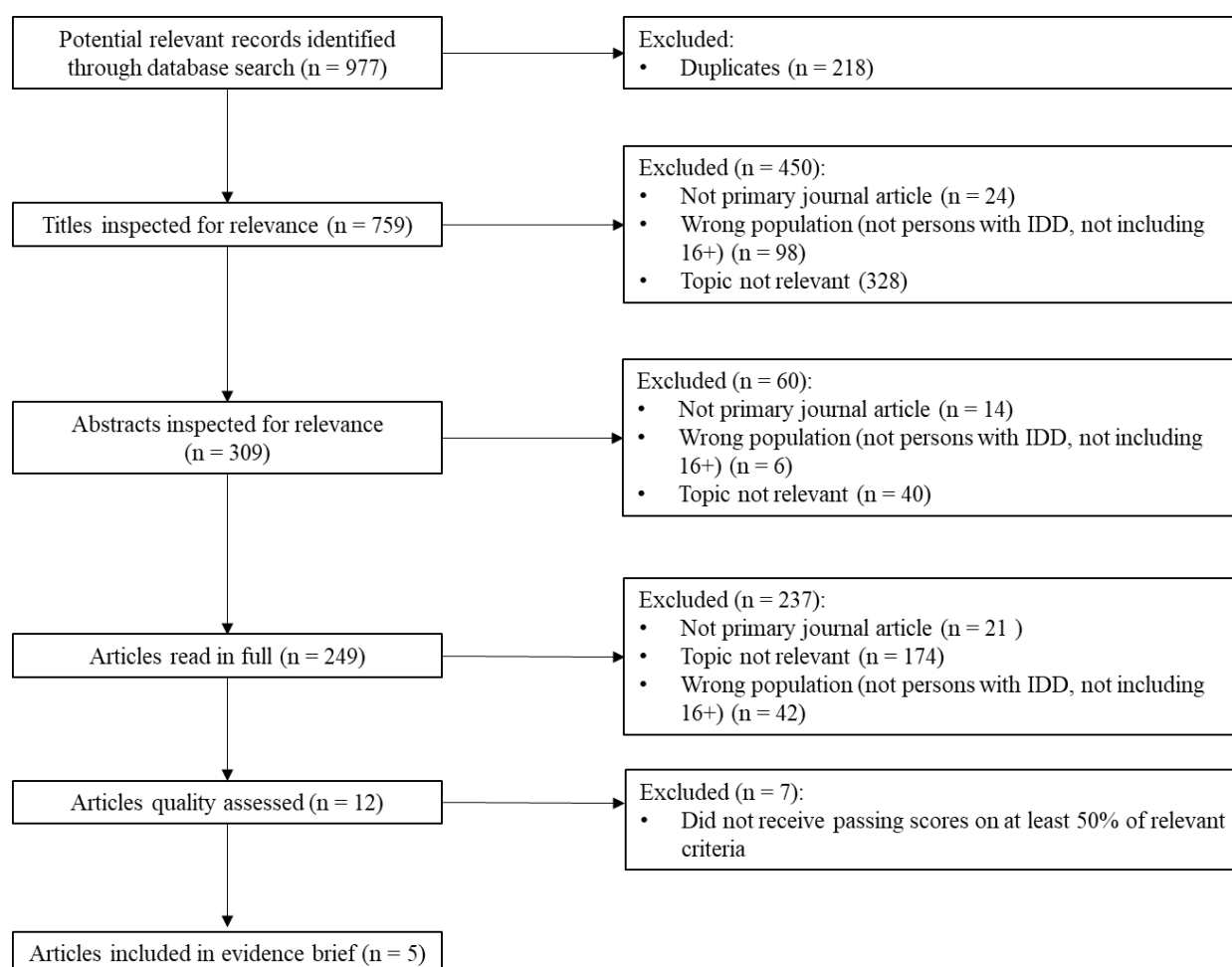


Figure 3.1. Systematic online database literature search findings and reasons for article exclusion

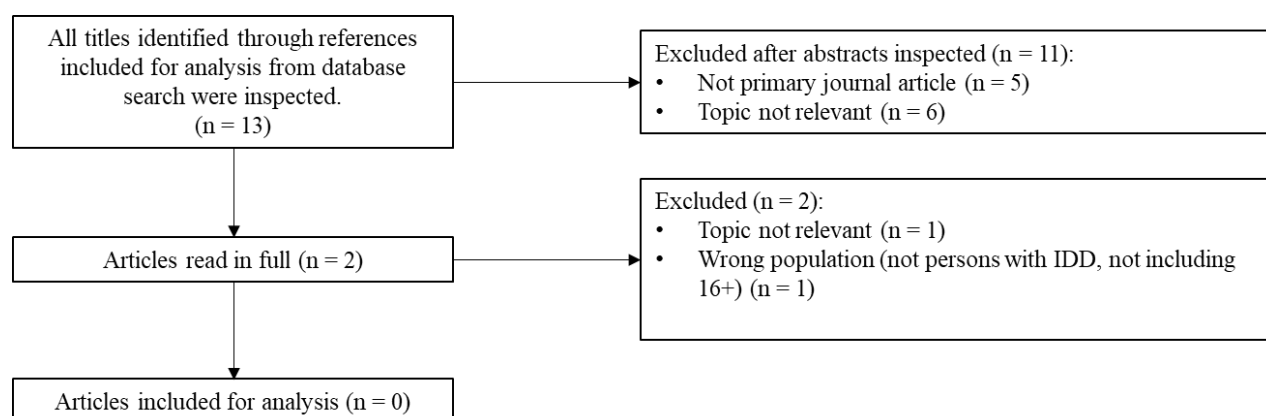


Figure 3.2. Hand search findings and reasons for article exclusion.

Table 3.1. *Quality Assessment of Included Studies*

Article Reference	Design	Screening Questions	Qualitative				Quantitative - Non-Randomized				Quantitative - Descriptive				Total Percentage		
	Qualitative vs. Quantitative	Quantitative Domain	S1	S2	1.1	1.2	1.3	1.4	3.1	3.2	3.3	3.4	4.1	4.2	4.3	4.4	
Hardman & Clark, 2006	Quantitative	Descriptive	0	1									1	0	1	1	75%
Hughes & Walden, 1999	Quantitative	Non-randomized	0	1					0	1	1	1					75%
McConkey et al., 2013	Qualitative		1	1	1	1	1	1									100%
McConnell et al., 2009	Quantitative	Non-randomized	1	1					0	1	1	1					75%
Werner et al., 1997	Quantitative	Non-randomized	1	1					1	0	1	1					75%

*Note*¹. Criteria S1 through 4.4 are from the Mixed Methods Appraisal Tool (MMAT; Pluye et al., 2011) [See Appendix B for criteria details.]. Only relevant criteria were included for this table (i.e., only for Qualitative, Quantitative Non-Randomized, and Quantitative Descriptive methods).

According to the Hierarchy of Study Designs to Assess the Effects of Interventions (University of York & NHS Centre for Reviews and Dissemination, 2009), the included articles were quasi-experimental (evidence level two) and observational studies (evidence level three). No randomized-controlled trials (evidence level one) were identified through the literature search. Table 3.2 provides detailed information about the level of evidence of each article, strategy descriptions, participant characteristics, and results related to strategy outcomes.

The included studies were conducted in Australia, Europe, and North America. Sample sizes ranged from four to 2367 participants, however three of the five studies used a sample size of less than 35 participants. Forty-eight percent of the participants with ID were female and 52 percent were male; one study included all female participants and one included all males. Participants with ID ranged from 12 to 78 years of age. The included five articles contained a variety of strategies to support friendships for individuals with ID. Strategies consisted of having volunteers facilitate interactions between individuals with ID and other people in the community (Hughes & Walden, 1999); volunteers from college partnering up with individuals with ID to form friendships (Hardman & Clark, 2006); weekly workshops that focused on meeting goals related to social relationships (McConnell, Dalziel, Llewellyn, Laidlaw, & Hindmarsh, 2009); sports teams with people with and without ID to foster friendships (McConkey, Dowling, Hassan, & Menke, 2013); and developing materials and systematically planning activities to support social interactions for people with ID (Werner, Horner, & Newton, 1997). Each strategy resulted in at least one positive outcome for participants (e.g., more positive attitude towards persons with ID, increased social skills, improved self-esteem). However, the long-term benefits of these outcomes were not systematically evaluated.

Table 3.2. *Characteristics of Selected Studies*

Strategy Title and Reference	Level of Evidence	Strategy Description	Sample Characteristics	Main Findings
Befriending Scheme (Hughes & Walden, 1999)	2	A “befriending agency” recruited volunteers through advertising in a local newspaper and interviewed interested volunteers. Volunteers without ID were paired with a group home where individuals with ID lived. They were expected to visit on a regular basis, over a 4 month period. Multiple volunteers were assigned to spend time with each individual with ID. Volunteers were expected to help individuals with ID increase the frequency of contact and size of their social networks by introducing them to new people and activities in the community. Volunteers received a 2-day group training, and on-going support was offered to volunteers by means of 2-hour facilitated group meetings on a monthly basis. Training included education about communicating with people with ID, rights and responsibilities of the volunteers, identifying the skill base and social networks of individuals with ID, and brainstorming ways to improve social networks. Group home staff received a half-day training about how to communicate and problem solve with the volunteers, the rights and responsibilities of volunteers, and details about the training that the volunteers received. Weekly meetings were provided for the individuals with ID to prepare them for the arrival of the befriending volunteers. These meetings continued throughout the program to explore how the individuals with ID felt about the program.	<u>Individuals with ID:</u> • $n = 4$ • Age: Range = 30-60 • Gender: F = 25%, M = 75% • Living arrangements: participants lived in a group home where they received 24-hour support. <u>Volunteers:</u> $n = 10$	<u>Attitudes towards individuals with ID:</u> • No information provided. <u>Impact on individuals with ID:</u> • Service-providers believed that the program facilitated the involvement of individuals with ID in outside activities, enhanced their social skills, and increased their self-esteem. • However, service-providers emphasized that new friendships should not be made at the expense of existing friendships and the importance of valuing friendships between people with ID. <u>Amount of social contact:</u> • Four months after implementation of the program only 1 volunteer was visiting. • Frequency of visits from members of social networks increased for 2 individuals with ID and decreased for 2 individuals. <u>Social network size and composition:</u> • Social network size increased for 1 individual with ID, stayed the same for 2 individuals, and decreased for 1 individual. <u>Activities engaged in:</u> • Overall, the total number of activities participated in increased across participants. However, for 1 participant the number of activities decreased.

Strategy Title and Reference	Level of Evidence	Strategy Description	Sample Characteristics	Main Findings
Australian Supported Learning Program (ASLP) - Me and My Community (McConnell et al., 2008)	2	The ASLP is a 12-week program directed towards mothers who have ID .A <i>Guide for Facilitators</i> and a <i>Participant Workbook</i> were developed to facilitate the implementation of this program. At the outset of the program, there were 10 specific program goals for which participants indicated their interest in achieving each specific goal (e.g., Meet people and make new friends, feel more confident about participating in groups). The program involved 8-10 weeks of group work using a problem-posing approach to adult learning. Each week, individuals with ID participated in a 2-hour group work session. Group work was followed by weekly home challenges to encourage participants to reflect on and practice what was discussed in the group. Group work was supplemented by individual support (phone contact and home visits) to assist participants with more specific and personal goals. Throughout the program, participants worked with a facilitator and the group, to reflect on personal experiences in the community, identify areas for improvement, identify 5 personal community involvement goals, make plans to achieve their goals, and ultimately implement those plans. This process involved: 1. Participants created a mural of their community to represent challenges in a tangible way; these murals would be used at each group session to help facilitate and focus the discussion topics. 2. They engaged in a guided 3-step questioning method to tackle challenges together, throughout each group meeting. Participants participated in guided action planning. The participants were taught how to break down the strategies into manageable tasks, to achieve their goals.	All participants were mothers with ID and had at least one child less than 5 years of age. All were able to participate in group discussion. Individuals lived in New South Wales and Victoria, Australia. <u>Individuals with ID</u> • N = 32 • Age: Mean = 34, Range = 17-48 • Gender: F = 100% • Ethnicity: Majority were born in Australia (91%) • Living arrangements: All individuals lived independently in: ○ Owned property = 22% ○ Rented property = 44% ○ Public housing = 34%	<u>Attitudes towards individuals with ID:</u> • No information provided. <u>Impact on individuals with ID:</u> • 84% of individuals achieved their first priority personal goal. • Each program goal was partially or fully achieved by at least 90% of participants. • Between 16% and 59% of participants felt they had not fully achieved each individual program goal (i.e., for each goal, at least 16% of participants wanted to keep working on fulfilling the program goal). • Overall, participant scores of depression decreased and social support scores increased. • Following the program, participants were more confident about getting involved in their communities, were more aware of opportunities and resources in their communities, and some were even inclined to take advantage of these opportunities by joining groups and classes within their communities. <u>Amount of social contact:</u> • No information provided. <u>Social network size and composition:</u> • No information provided. <u>Activities engaged in:</u> • No information provided.

Strategy Title and Reference	Level of Evidence	Strategy Description	Sample Characteristics	Main Findings
Best Buddies College Program (Hardman & Clark, 2006)	3	This is a strategy to foster friendships between individuals with and without disabilities. The Best Buddies College Program facilitated one-to-one friendships between college students without disabilities and individuals with ID. Students who were interested in volunteering submitted applications (which included a survey about their personality and interests) and underwent an interview by Best Buddy service-providers. Partners (volunteers and individuals with ID) were matched based on common interests and personalities. Best Buddies service-providers made sure that both partners enjoyed the activities they engaged in. For the duration of one year, volunteers committed to: a) contacting their partner on a weekly basis (phone call, letter, e-mail, or in-person), b) having a one-on-one activity with their partner 2-3 times each month, and c) attending Best Buddies chapter meetings and group activities.	All participants lived in the United States; the majority in California, Florida, and Texas. All individuals were able to answer survey questions verbally or in writing. <u>Individuals with ID:</u> • $n = 1,145$ • Age: Mean = 32, Range = 12-78 • Gender: F = 51%, M = 48%, unknown = 1% • Ethnicity: primarily Caucasian (69%) <u>Volunteers:</u> • $n = 1,222$ • Age: Mean = 20, Range = 17-51 • Gender: F = 80%, M = 17%, unknown = 3% • Ethnicity: primarily Caucasian (76%)	<u>Attitudes towards individuals with ID:</u> • 80% of volunteers had more positive attitudes about the abilities of people with ID. <u>Impact on individuals with ID:</u> • Over 40% of individuals with ID were more comfortable in social settings, speaking up for themselves, and participating in the community. • 60% of individuals with ID said making friends in the program had enhanced their lives. • 80% of partners enjoyed the program and would participate again. <u>Amount of social contact:</u> • 50% of partners spoke to each other on the phone at least once per month. • 78% of volunteers and 71% of individuals with ID participated in either a one-to-one activity or a planned group activity on a monthly basis. • Individuals with ID consistently expressed that they did not see their partners as much as they would like or as much as the program suggested (2-3 outings each month). <u>Social network size and composition:</u> • No information provided. <u>Activities engaged in:</u> • Friendship: telephone calls, going to movies, eating at restaurants, sporting events, outdoor recreation, spending time together at home • Teaching: social skills, use of transportation, job skills, and finances

Strategy Title and Reference	Level of Evidence	Strategy Description	Sample Characteristics	Main Findings
Unified Sports (McConkey et al., 2013)	3	This is a strategy to develop friendships between young people with and without ID through sports, and provide opportunities for community inclusion among individuals with ID. The Unified Sports program of Special Olympics brought together individuals of a similar skill level on the same sports teams for frequent training and competitions. The teams trained regularly and competed with other Unified Sports teams at the local, national, and international level. The Unified Sports programs took place in schools, Special Olympics clubs, and sports clubs within the community.	Participant lived in Europe (Serbia, Poland, Ukraine, Germany, and Hungary). <u>Athletes with ID</u> • $n = 156$ • Age: Range = 12-25 (56% were 16-25) • Gender: F = 19%, M = 81% • Living arrangements: One third lived in institutions or boarding schools, and two-thirds lived with family members. <u>Athletes without ID</u> • $n = 106$ • Age: Range = 12-25 (79% were 16-25) • Gender: F = 13%, M = 87% • Living arrangements: Majority lived with family members. <u>Coaches</u> • $n = 65$ Gender: F = 25%, M = 75%	<u>Attitudes towards individuals with ID:</u> • Individuals without ID began to respect those with ID more, and began to better recognize their abilities. <u>Impact on individuals with ID:</u> • Individuals with and without ID became more confident and comfortable socializing with one another. • Individuals with ID experienced increased self-confidence and social status among peers in community. • People with ID experienced improved interpersonal skills (i.e., more confidence, less shyness, stated opinions more, less afraid of strangers). • Team members were treated as equals by each other and by coaches. • All participants agreed that the program led to more social inclusion and increased opportunities to engage in community life. <u>Amount of social contact:</u> • No information provided. <u>Social network size and composition:</u> • No information provided. <u>Activities engaged in:</u> • Friendships developed among teammates on and off the field. Teammates engaged in many non-sports activities together. • When inclusive and equal bonds were less evident amongst athletes with and without ID, there was less joint participation in community settings.

Strategy Title and Reference	Level of Evidence	Strategy Description	Sample Characteristics	Main Findings
Barrier Reduction Package (Werner et al., 1997)	3	This is a strategy to reduce social barriers for people with ID. Personalized barrier reduction packages were developed. The barrier reduction packages included the following components: 1. <u>Personal schedule</u>: Social activities were noted in a weekly date book. 2. <u>Social activity scheduling</u>: Social activities were planned and marked in individual's personal schedule for the up-coming week at weekly meetings. 3. <u>Personal information sheet</u>: 1-2 page descriptions of the individual with ID, to be used when meeting new people. Included information that 'friends should know', such as birthplace, places lived, names of parents and siblings, activity preferences, personal accomplishments, etc. 4. <u>Friendship form</u>: 1 page of information about people in the community who did activities with participant including their name, address, telephone number, and activities done together. 5. <u>Photo address file</u>: Pictures and information about friends, so that the individual could select who they wanted to contact. 6. <u>Photo activity file</u>: Pictures of different activities, to select and convey preferences. 7. <u>Weekly feedback</u>: Service-providers wrote weekly summaries about participant social activities and reviewed summaries at weekly meetings. Service-providers were informed about the importance of relationships, the activities that the individuals with ID currently engage in, barriers to social contact, and were provided with an introduction to the barrier reduction package. Researchers supported the service-providers to develop the required barrier reduction packages and provided guidance on implementation.	Individuals lived in Oregon, United States. <u>Individuals with ID</u>: • $n = 3$ • Age: Mean = 33.66, Range = 30-40 • Gender: M = 100% • Living arrangements: Residential support, with at least 2 service-providers for all 3 individuals, at any given time. • Support level: non-verbal and requiring 24-hour support <u>Service-providers</u>: • $n = 19$ • Age: Range = 19-44	<u>Attitudes towards individuals with ID</u>: • No information provided. <u>Impact on individuals with ID</u>: • After 6 months, service-providers had used/implemented at least 6 components of the Barrier Reduction Package. <u>Amount of social contact</u>: • No information provided. <u>Social network size and composition</u>: • The number of different people with whom activities were engaged in on a weekly basis increased for 2 of the participants. <u>Activities engaged in</u>: • The number of social activities engaged in on a weekly basis increased for 2 of the participants. • All participants started to visit other people at their homes more frequently. • All participants began engaging in community activities that they had not previously done, such as visiting friends, shopping, running errands and participating in music and leisure events.

Conclusion

Limitations

Due to limited research on this topic, we opted for fairly broad inclusion criteria in an attempt to capture as much relevant research as possible. However, this led to wide variation between included studies in terms of participant characteristics and support needs. Therefore, it is difficult to meaningfully compare the impact of the five friendship facilitation strategies, as the populations in which they were assessed are very different. When implementing a strategy to support the relationships of people with ID, it is important that community-based organizations are aware of the level of support needs of the population that was studied.

This review only included studies that were published in English; findings from this review are primarily representative of participants' experiences from English speaking, western cultures (Australia, Europe, and North America). However, one study (McConkey et al., 2013) also included participants from Serbia, Poland, Ukraine, Germany, and Hungary. When selecting friendship support strategies to implement in community-based organizations for individuals with ID, it is important to consider the context (e.g., country, language, cultural values) that it was implemented in to determine if it would be an appropriate fit for the local setting.

The Google search engine was used for the grey literature search. Google ranks webpages based on a number of factors (Google, 2017). One main factor is the number of times other webpages link the target webpage. It is possible that there were studies that met inclusion criteria, but were not high enough ranked by Google to appear on the first four pages of search results.

Implications and Future Directions

Overall, the quality of the evidence for the identified strategies was low. In addition, two of the strategies were implemented and assessed using sample sizes of less than five participants, and these studies focused on individuals who had high levels of support needs. In contrast, the studies focusing on individuals with fewer support needs had approximately 30, 150, and 1150 participants with ID. It is plausible that the strategies targeting individuals with higher support needs are less generalizable than those targeting individuals with low support needs. Each strategy resulted in at least one positive outcome for participants. However, one article (Hughes & Walden, 1999) indicated that the strategy implementation may have resulted in new friendships developing at the cost of existing relationships. Additional research is required to systematically compare the magnitude of the effects of different strategies, especially for individuals who have varying support needs. Given the emphasis placed on social inclusion and the importance of this area to individuals with ID and their caregivers, it is surprising how few strategies to support friendships have been evaluated.

Although rights promoting social inclusion of individuals with disabilities have been internationally emphasized (United Nations, 2006), this has evidently not resulted in friendship support as a research priority for individuals with ID. People with ID desire more friendships and often require assistance from caregivers and service-providers to develop and maintain friendships (Brackenridge & McKenzie, 2005; Cummins & Lau, 2003; Emerson & McVilly, 2004; Knox & Hickson, 2001; Mason et al., 2013; Weafer, 2010). In response, community-based organizations have developed programs that support the social relationships of people with ID. However, without proper evaluation of these programs, service-providers cannot ensure that their

friendship support practices actually enhance the social lives of individuals with ID (Wholey, Hatry, & Newcomer, 2010).

Service-providers and family caregivers have indicated that they need more training to support friendships (Evans, McGuire, Healy, & Carley, 2009). There are a number of strategies that have been developed to support friendships for people with ID in community-based settings. However, findings from the current review suggest that there is a paucity of high-quality research that systematically evaluates existing friendship support strategies. In addition, there are limited tools that mobilize key findings of extant research so that it can be used by stakeholders.

Clearly, there is a need to implement evidence-based strategies to support friendships for individuals with ID. However, we do not yet know the best way to collaborate with community-based organizations in order to incorporate research findings into practice. For individuals with ID to receive evidence-based friendship support services, research results should be accessible to, and shared with, community-based organizations. Findings from this review can be used by organizations to better support the friendships of people with ID. Although the quality of research may be low, the review highlights various factors that community-based organizations should consider to improve upon and implement existing strategies to support the friendships of persons with ID. When implementing these friendship support strategies in community-based organizations, strategies will have to be adapted to meet the needs and resources of stakeholders (e.g., individuals with ID, caregivers, and service-providers) (Graham, Tetroe, & KT Theories Research Group, 2007; Grol & Wensing, 2013).

SECTION 3: Assessing a Knowledge Mobilization Process in Community-Based Social Settings to Foster Friendships for Individuals with Intellectual Disabilities

After providing a conceptual discussion of the principles for using knowledge to inform practice (Section 1), and completing a substantive review of the current context of friendships of adults with intellectual disabilities (ID) (Section 2), the current section consists of empirical findings from two primary research studies. We evaluated knowledge mobilization activities in community-based services, aimed at fostering friendships for adults with ID. To conduct this research, we collaborated with a variety of stakeholders associated with community-based organizations.

Chapter 4: A Process Evaluation of Knowledge Mobilization in Community-Based Services: A Case of Friendship Support for Adults with Intellectual Disabilities

Fulford, C., & Cobigo, V. (2019). *A process evaluation of knowledge mobilization in community-based services: A case of friendship support for adults with intellectual disabilities.*

Unpublished manuscript.

Contribution

Author Contributions

Casey Fulford, the primary author, conducted data collection with the service-organization, conducted data analysis, and wrote the majority of the paper content

Dr. Virginie Cobigo, the supervising author, facilitated recruitment throughout the service-organization, and met with Ms. Fulford frequently to discuss the research questions, data collection, and data analysis. Throughout the process, Dr. Cobigo provided guidance and recommendations regarding article content and edited the full paper.

Acknowledgements

I sincerely appreciate all the time and effort provided by the community-based organization with whom we partnered to evaluate knowledge mobilization activities. I would like to thank the director of the organization and the advisory team staff members for their contributions to this research. I am also very grateful to the caregivers and service-users who shared their experiences and opinions with me.

Funding

There was no funding provided for the completion of this paper

Preamble

The primary objective of this dissertation was to conduct an evaluation of a knowledge mobilization (KM) process in a community-based organization that supports individuals with intellectual disabilities (ID). The research activities described in this chapter aligned with the Grol and Wensing Implementation of Change Model (2013). We provided detailed information on the steps of the model, and described how our research activities mapped on to those steps. We then presented findings from the natural field experiment about KM focused on friendship support strategies for adults with ID. We explored how KM activities were implemented and how stakeholders collaborated throughout the process.

Abstract

Knowledge mobilization (KM) is a process that involves researchers and knowledge users exchanging and co-creating knowledge to change practices and policies. Scarce evidence is available to inform KM practices in community-based services. We aimed to conduct an evaluation of the KM process to understand 1) What factors influenced the process of KM in community-based supports for adults with intellectual disabilities (ID) and 2) When and how these factors contributed to the disruption of the KM process. We partnered with an organization that provides community-based social support to adults with ID. We conducted a thematic analysis of qualitative data that was collected throughout the KM activities: a) advisory committee meetings, b) focus groups with service-users, c) focus groups with caregivers, and d) a follow-up interview with the agency director. Factors affecting both the success and disruption of the KM process were grouped under three themes: Knowledge, Commitment and Consistency, and Communication. These factors played varying roles throughout the KM process. Key practical recommendations for successful KM were: 1) Clear terms of reference for the advisory committee is necessary, 2) Engagement of stakeholders should be a focus throughout the process, 3) Methods of communication should be adapted for the type of information being conveyed, and 4) Understanding the unique local context in which KM is taking place.

Introduction

Knowledge mobilization (KM) provides an avenue for improving supports and outcomes for persons with intellectual disabilities (ID) (Kersten, Taminiau, Schuurman, Weggeman, & Embregts, 2018). KM is a process that involves researchers and knowledge users exchanging knowledge and co-creating new knowledge in order to enhance practices and policies (Bennet et al., 2007). According to Abma and colleagues (2017), “the process of knowledge mobilization values different types of knowledge alongside scientific research, focusing on what different types of people know, rather than assuming what one ought to know” (p.92). To improve supports for individuals with ID, evidence-based knowledge (i.e., research findings) must be integrated with practice-based knowledge (i.e., service-provider knowledge developed through reflecting on what they have learned) and experiential knowledge (i.e., service-user knowledge based on life experiences) (Kersten et al., 2018; Schalock, Verdugo, & Gomez, 2011).

There are a multitude of models describing the KM process (Rossi, Lipsey, & Freeman, 2003), which typically outline a series of steps to follow in order to implement change (Nilsen, 2015). However, there are some concerns regarding existing models. Firstly, many models used in implementation research are vague regarding how to share and use knowledge (Tabak et al., 2017; Ward, 2017). KM models do not typically provide details regarding the specific operations and resources required (Davies, Powell, & Nutley, 2015; Graham, Tetroe, & KT Theories Research Group, 2007). Secondly, the scientific basis underlying KM models still needs to be examined, as models describing how to move research into practice are rarely systematically evaluated (Grol & Wensing). Lack of evaluation means that the activities underlying these theories are often not evidence-based (Davies, Powell, & Nutley, 2015; Grimshaw, Eccles, Lavis, Hill, & Squires, 2012). By evaluating KM in applied settings, we can develop more

specific and practical recommendations regarding ways to effectively build relationships between stakeholders, communicate clearly, and work within the existing political climates of organizations (Davies et al., 2015).

Process Evaluation

Grol and Wensing (2013) identified common features of process theories of KM and developed a comprehensive model which included those elements. Notably, they have included continuous evaluation of the KM activities throughout the entire process. Typically, when evaluation of KM does occur it often focuses on outcomes rather than exploring the processes underlying how these outcomes are obtained (Davies et al., 2015). The way in which KM activities are delivered and the experiences of different stakeholders during the process affect whether or not changes in practice occur. Thus, it is important to explore the roles of all stakeholders and examine how to share evidence-based, practice-based, as well as experiential knowledge, when engaging in activities to change practices (Kersten et al., 2018). It is also imperative to evaluate the success and disruption of KM processes and to consider the organizational contexts in which these processes are carried out (Cooper, 2014). A process evaluation seeks to clarify the underlying mechanisms of KM that lead to changes in practice (or lack thereof), and illustrate the feasibility and utility of different aspects of KM (Hulscher, Laurant, & Grol, 2013). By examining how key players communicate and collaborate within and between stakeholder groups, we can gain a comprehensive understanding of the mechanisms associated with the success or disruption of KM. Using a KM approach informed by the Grol and Wensing Model (2013) would facilitate conducting a process evaluation.

Theoretical Model

The research methods in this study were informed by Grol and Wensing's Implementation

of Change Model (Grol & Wensing, 2013), as well as a detailed guide regarding each step of the model, which is supported by existing implementation science literature (Grol, Wensing, Eccles, & Davis, 2013). This model was selected because it is based on the review and synthesis of a multitude of theories regarding knowledge sharing and implementation of change (Grol & Wensing, 2013). Furthermore, this model aligns with key steps of planned action models that have been identified by other researchers who focus on using knowledge to change practices (e.g., Graham et al., 2007). The model lends itself well to conducting a process evaluation, as evaluation is a crucial and ongoing component in the Grol and Wensing Implementation of Change Model.

Purpose

The aim of this research project was to conduct a process evaluation of KM activities in the context of an organization providing community-based supports to persons with ID. Our specific objective was to provide practical recommendations to inform KM practices. The research questions were: 1) What factors influence the process of KM in an organization that provides community-based support, and 2) When and how did these factors may contribute to the success and disruption of the KM process?

Method

Ethics

Ethics approval was obtained from the Research Ethics Board at the University of Ottawa prior to beginning data collection, as well as for publication of all findings.

Context

We partnered with an organization that provides community-based social support to adults with ID, in Ontario, Canada. The organization supports approximately 100 service-users

with mild to moderate support needs. The senior researcher has collaborated with the organization on prior projects. This organization was selected due to their interest in the study, as well as their commitment to support persons with ID to experience reciprocal relationships.

Procedure

See Figure 4.1 for a summary of the steps of the model and our intended research activities. Then, we describe all intended research activities.

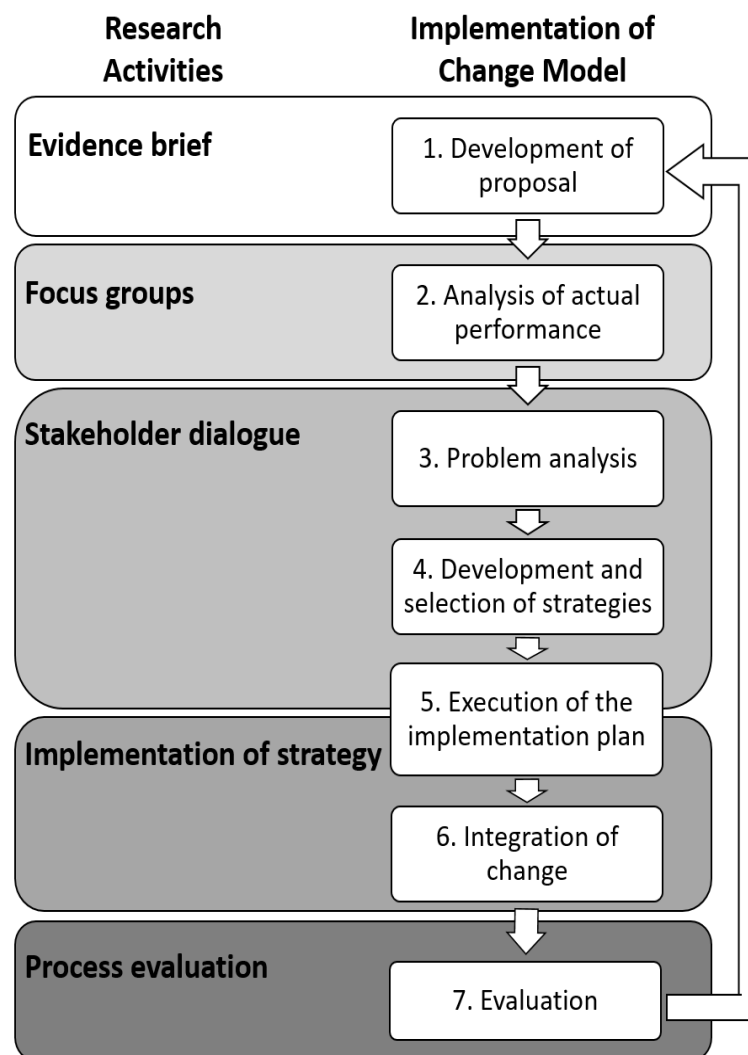


Figure 4.1. Summary of the Grol and Wensing Implementation of Change Model and intended research activities. Figure adapted from Grol & Wensing (2013, p. 46). Used with permission.

Advisory committee. Given that the researchers were external to the community-based organization, we planned to consult with an advisory committee consisting of four to eight staff members on a monthly basis. Throughout the KM process, we expected that advisory committee members would support recruitment, data collection, and contribute to decisions regarding how to tailor research methods to the needs of service-users with ID and to align with values of the organization. At each advisory team meeting, we planned to have a researcher take notes on the topics discussed, decisions made, and next steps to be taken.

Step 1: Development of a proposal for change. The aim of the first step was to provide information to stakeholders at a community-based service organization, regarding strategies to support friendships among persons with ID. We planned to conduct two literature reviews to 1) summarize the barriers to forming and maintaining relationships and the support needs of individuals with ID, and 2) summarize and critique the existing evidence regarding strategies for supporting friendships among individuals with ID. Using this information, we intended to develop an evidence brief (informed by The SURE Collaboration, 2011) to update stakeholders about possible strategies to better support friendships. We planned for the evidence brief to include information regarding the challenges experienced by caregivers when providing friendship support, descriptions of evidence-based strategies to support friendships for individuals with ID, and the results of the articles that presented the evaluation findings from the included strategies. In addition, practical implementation considerations informed by the SURE Collaboration (2011) would be provided.

Step 2: Analysis of actual performance and targets for change. We planned to examine current practices of the community-based organization and identify differences from researched friendship strategies. We then intended to conduct four focus groups: two with adult

service-users with ID and two with family caregivers. During the focus groups, we intended to facilitate discussions on the friendship supports service-users receive, quality of the support, and additional needs with regard to friendship development. We then planned to present the strategies that we had identified through the literature review (Step 1), seek participants' perspective regarding the utility of these strategies, and obtain suggestions for implementing them within the organization. [See Appendix C to view the focus group protocol]. Focus groups were intended to be conducted at the organization, last 90 minutes, be audio recorded, and transcribed verbatim. Summaries of the focus group findings would then be incorporated into the next iteration of the evidence brief.

Step 3: Problem analysis of target group and setting. The purpose of this step was to understand stakeholders' aims regarding friendship support, and to explore facilitators and barriers to change within the organization. This step was intended to be partially completed during focus groups with service-users and family caregivers, which elucidated their goals regarding friendship support. The remainder of Step 3 was intended to be completed during a stakeholder dialogue (details below), in which we would also obtain the perspectives of service-providers and then explore facilitators and barriers to change

Step 4. Development and selection of strategies and measures to change practice

The purpose of Step 4 was to select strategies to be implemented within the community-based organization. We intended to select a strategy or a combination of strategies during a stakeholder dialogue, which is a structured discussion amongst stakeholders, including service-users, service-providers, and family caregivers. A stakeholder dialogue focuses on a topic (i.e., friendship) covered in an evidence brief. We had planned for the evidence brief, which would include

information obtained from literature reviews and a summary of the service-user and family caregiver focus group discussions, to be distributed to stakeholder dialogue participants at least two weeks prior to the stakeholder dialogue. The stakeholder dialogue was intended to follow the same structure as the evidence brief; the group would discuss the included strategies, barriers to implementation of different strategy, engage in problem-solving regarding implementations, and it was the intention that ultimately a strategy or combination of strategies would be selected to implement. Stakeholder dialogues were intended to take place at the service agency, last half a day, and be audio recorded and transcribed.

Step 5. Development, testing, and execution of implementation plan & Step 6.

Integration of changes in routine care

The purposes of Steps 5 and Step 6 were to implement the selected strategy and integrate change into routine and sustained practices. At the stakeholder dialogue, we intended to select an implementation team who would take the lead on implementing the strategy. The researcher would then collaborate with the team to develop project timelines and determine intermediate deliverables during the implementation process. The primary researcher planned to attend one hour bi-weekly meetings, write meeting minutes, and provide recommendations for the implementation of the strategy. The service agency would be allotted up to six months to implement the strategy. If the implementation phase continued after six months, the researchers would stop evaluating the process to ensure feasibility of the study and because we did not intend to conduct an outcome evaluation.

Step 7: Evaluation of the implementation process. This step would consist of an evaluation of the whole KM process. To evaluate the KM process, we intended to analyze

advisory committee meeting minutes, focus group transcripts, the stakeholder dialogue transcript, a questionnaire administered after the stakeholder dialogue, implementation meeting notes, and research memos. Throughout all KM activities, the primary investigator planned to write research memos, which are systematic notes explaining why changes were made to the intended research activities (Miles, Huberman, & Saldaña, 2013).

Data Analysis

Advisory committee meeting minutes and transcripts of the focus groups with persons with ID and with caregivers, as well as transcripts of the interview with the director were imported into QSR NVivo 11. We conducted a qualitative thematic analysis of the data, which aims to identify recurring ideas (Riger & Sigurvinsdottir, 2015). First cycle coding consisted of deductive and inductive analysis (Miles et al., 2013). We reviewed all raw data and developed a list of deductive (i.e., a priori) codes (Braun & Clarke, 2006; Miles et al., 2013), which focused on identifying facilitators and barriers to KM. We then applied the a priori list of codes to the data and flexibly revised the list as necessary to best fit the data (Braun & Clarke, 2006; Miles et al., 2013). During second cycle coding, we engaged in an iterative process to cluster related codes together to identify themes. The primary author wrote analytic memos during data analysis to facilitate data synthesis and theme identification (Miles et al., 2013). The authors met regularly to review and adapt the coding structure.

To understand the rationale for why some KM activities ultimately differed from the intended activities, we reviewed research memos, advisory committee meeting minutes, and the transcript of an interview with the director of the community-based organization. These findings contributed to our understanding of the way that different factors affected KM at different steps in the process.

Findings

As planned, we formed an advisory committee and completed Step 1 (produced an evidence brief), Step 2 and part of Step 3 (conducted focus groups with service-users and caregivers) of the Grol and Wensing (2013). However, the KM process was terminated during Step 3 (when planning the stakeholder dialogue). Therefore, we did not complete the stakeholder dialogue or implementation of a strategy. In the below sections, we summarize each step and provide details on how it was conducted. We also discuss the disruption of the KM process and rationale for discontinuation. We then thematically discuss the barriers and facilitators that influenced KM at each step of the process. The barrier and facilitator themes that we identified include: A) Knowledge, which refers to the type of knowledge shared throughout the process (i.e., evidence-based knowledge, practice-based knowledge, and experiential knowledge); B) Commitment and Consistency, which refers to stakeholder engagement in KM activities; and C) Communication, which refers to the type of content discussed and the methods used to communicate between stakeholders. The following sections are organized according to the steps of the Grol and Wensing Model (2013) that we outlined in the methods section.

Advisory committee

The advisory committee consisted of staff members ($n = 5$), who were selected by the director of the community-based organization. The director reported that they selected advisory committee members based on the information the researchers provided about the study and the advisory committee member duties (e.g. participant recruitment, providing feedback regarding accessible language, decision making regarding research methods). The director indicated that the committee members had the requisite skills and access to the organization's resources to effectively collaborate with the researchers, service-users, and caregivers.

The terms of reference were not determined at the formation of the advisory committee. Throughout the KM process, advisory committee members volunteered to complete tasks as they arose. Discussions and decisions focused on tailoring research documents and activities to maximize accessibility for participants (adult service-users with ID and caregivers) and to align with the organization's values and capacities. At each meeting, a research assistant took notes on the topics discussed, decisions made, and next steps to be taken. We collaborated with the advisory committee and conducted KM activities with the community-based organization over the course of 8 months from February to October 2017.

A) Knowledge. Practice-based knowledge was an important facilitator when developing and consulting with the advisory committee. The director of the organization selected staff who worked directly with service-users to be on the advisory committee. They had diverse knowledge about the organization's programs and about supporting individuals with ID. They also had sufficient understanding of the organization's service-users and knowledge of how to contact and recruit service-users and caregivers for focus groups. Therefore, the advisory committee took the lead on recruiting participants for focus groups. This excerpt from advisory meeting minutes provides an example of the type of information and suggestions provided by advisory committee members:

[Advisory committee member] brings up that there is a bias [in participant selection] in that service-users who are still involved with [organization] have a good relationship with the organization. Discuss[ion] that this positive bias may be unavoidable as [organization] is the gatekeeper of info on service-users, should try [to recruit] a variety of service-users to get a broader perspective.

Practice-based knowledge of advisory committee members informed decision-making during the KM process. Both the director's and the advisory committee members' practice-based knowledge were facilitators during advisory committee development and when consulting with the advisory committee.

B) Commitment and consistency. Initially, the director appeared engaged and motivated to participate in the project. However, after the initial contact between the advisory committee members and the researchers, the director opted not to be involved in decision-making regarding KM activities. Advisory committee members initially appeared engaged and committed to the KM process. They raised questions and concerns about research activities, provided suggestions for increasing accessibility, and gave the researchers relevant information about the organization.

Throughout the KM process, advisory committee membership was inconsistent. Initially, four front-line staff agreed to be on the committee ($n = 4$). During the second month of KM activities, one individual stopped working at the organization and their spot on the advisory committee was not filled ($n = 3$). Within the same month, an advisory committee member position that was initially filled by a temporary staff member was replaced by a permanent staff member ($n = 3$, 2 original members). During the sixth month of working with the advisory committee, after the focus groups had been conducted and prior to the stakeholder dialogue, another staff member left the organization and their position was not filled ($n = 2$, 1 original member). However, inconsistencies in advisory committee membership did not appear to negatively impact the KM process, for Steps 1 and 2, prior to the completion of the focus groups (i.e., advisory committee member activities proceeded as planned during the first two steps).

C) Communication. In between bi-monthly meetings with the advisory committee, communication between the primary researcher and advisory committee members was conducted

via email. This proved to be an effective mode of communication when discussing focus group logistics (e.g., time, location, reminder phone calls) and scheduling in-person advisory committee meetings.

At the outset of the KM process, the researchers did not provide instructions regarding the director's level of involvement. During the follow-up interview, the director reported that the advisory committee had assigned a specific member (who was on the committee throughout all KM activities) to provide updates to the director about the KM process. The director indicated that the advisory committee member gave updates frequently. However, based on the information provided by the director in the follow-up interview, these updates did not appear to include specific details regarding decisions made by the advisory committee, rather they discussed the more general KM activities.

Step 1: Development of a Proposal for Change – Evidence Brief.

As planned, we conducted two literature reviews [Chapters 2 & 3], which were used to develop the evidence brief. The evidence brief (Fulford, Cobigo, & Ressel, 2017) included the intended content regarding the challenges experienced by caregivers when providing friendship support, descriptions of evidence-based strategies to support friendships for individuals with ID, the results of the articles that presented the evaluation findings from the included strategies, and practical implementation considerations. [See Appendix D for a de-identified version of the evidence brief.]

A) Knowledge. Evidence-based knowledge was an important factor when developing the evidence brief. In December 2016, we conducted a systematic literature review to identify and summarize friendship support strategies for adults with ID that had been evaluated. There was a paucity of recent research on this topic using study designs that yielded strong evidence.

Ultimately, five studies, which received a total score of at least 50% on Mixed-Method Appraisal Tool (Pluye et al., 2011), were included in the evidence brief (Fulford et al., 2017). These studies were published in 1997, 1999, 2006, 2008, and 2013.

B) Commitment and consistency. The research team conducted the literature review and wrote the evidence brief according to the original research proposal. There was no involvement of the community-based organization at this stage of the process.

C) Communication. The primary researcher sought out the authors of the original articles to obtain additional information regarding implementation of strategies. All original authors responded and provided additional details when they had relevant information. This communication facilitated KM, as some additional information was obtained that was then included in the evidence brief.

Step 2: Analysis of Actual Performance and Targets for Change – Focus Groups.

As planned, we conducted two focus groups with service-users with ID and two with caregivers. During the focus groups, we facilitated discussions on the friendship supports service-users receive, quality of supports and services, and additional needs with regard to friendship development. We then presented the strategies that we had identified through the literature review, sought participants' perspective regarding the utility of these strategies, and obtained suggestions for implementing them within the organization.

Service-users ($n = 7$) ranged in age from 22 to 42 years ($M = 34.71$, $SD = 6.42$). Fifty-seven percent were female and 43% percent were male. Forty-three percent of the service-users attending the focus groups lived alone, 28.5% lived alone and received part-time support from staff, and 28.5% lived with their parents. Caregivers who attended the focus groups ($n = 10$) ranged in age from 52 to 70 years ($M = 61.60$, $SD = 6.20$). Eighty percent were female and 20%

were male. All female caregivers were mothers of individuals with ID. One male caregiver was a father and another was the roommate of an individual with ID. The caregivers were connected with nine individuals with ID; two of whom attended the service-user focus groups and seven who did not. These nine individuals ranged in age from 22 to 43 years ($M = 32.55$, $SD = 6.26$). Thirty-three percent were female and 67% were male. Eleven percent lived in a group home, 33.5% lived with their parents, 11% had full-time staff support, 11% lived alone and received part-time staff support, and 33.5% lived alone.

A) Knowledge. Service-users and caregivers provided a variety of practical suggestions for adapting and implementing friendship support strategies, based on their experiential knowledge. However, some individuals with ID had difficulty comprehending strategies when they had not received similar supports in their own lives. To better understand the hypothetical strategies that were being discussed, they often referred back to experiences they had when receiving similar supports; they were then able to provide meaningful suggestions for implementation. For example, when asking participants what they thought of a strategy for which service-users and other members of the community would play on integrated sports teams, one service-user reported that she had difficulty when playing on a sports team in the past and would prefer integrated sports teams. She also provided relevant implementation suggestions, based on her past experiences:

Service-User: Yeah, like I mean that would be probably- because I've tried [another organization]. For me I found it [group sport] too- too hard because they- I found that the level was like a little bit like not my level [...]

Service-User: But I would have fun [...] I would be able to like play, it would be at my level...[if adapted for individuals of varying level of support needs]

Service-User: A lot of people might like [adapted sports], we might have, may have different rules [...], be[cause] [...] there's different disabilities [of different service-users].

Despite service-users experiencing some challenges comprehending strategies, their experiential knowledge was a facilitator to KM, as concrete suggestions could readily be summarized in the evidence brief.

B) Commitment and consistency. Advisory committee members recruited participants, assisted with focus group logistics, and conducted reminder phone calls. Leading up to and during the focus groups, the advisory members' commitment was a major facilitator to the KM process. During the focus groups, service-users and caregivers appeared very committed and interested in friendship supports. All focus group participants contributed to the discussions and provided a range of perspectives on current services and suggestions for implementing strategies. Focus group participants appeared highly motivated to partake in the KM process. For example, when asked if they wanted to take part in the next step of the KM process, the stakeholder dialogue, service-users responded positively:

Researcher: We are going to pass on all of this information to [organization] and then, you will be invited to the bigger meeting [stakeholder dialogue].

Service-User: I would love to, I'm going to be in that group. I want to be in that group.

Furthermore, all focus group participants who could be reached via telephone after the focus groups agreed to attend the stakeholder dialogue. The commitment of service-users and caregivers was a facilitator to the KM process. However, it should be noted that their ongoing

commitment could not be evaluated, as focus group participants did not have the opportunity to be involved in KM activities over a sustained period of time.

C) Communication. During focus groups with service-users, we attempted to do a hands-on activity, when obtaining feedback on friendship support strategies from past literature. We provided cards with different strategy descriptions and asked participants to indicate their opinions about each strategy using green (positive feelings), yellow (neutral/mixed feelings), and red (negative feelings) markers. This proved to be more confusing than helpful, as service-users indicated they did not understand the instructions, even when repeated in different ways. However, when using clear language (without the hands-on activity) to explain the strategies, participants with ID were able to provide relevant feedback.

Steps 3-5 – Stakeholder Dialogue

We had intended to complete a stakeholder dialogue with service-providers, service-users, and family caregivers to understand the aims of all stakeholder groups, explore facilitators and barriers to change within the organization, select a friendship support strategy, and identify an implementation team. However, before we could engage in these activities, the community-based organization indicated that did not intend to continue with the KM process. After further discussion with the director of the organization, the researchers agreed that the best course of action was to stop the KM process.

Email communication indicates that the researcher sent a reminder to distribute the evidence brief two weeks prior to the stakeholder dialogue. However, in a follow-up interview with the director of the organization they indicated that the document was not sent to staff, which the advisory committee reported was because they forgot to do so. Three days prior to the

stakeholder dialogue, an advisory committee member reviewed the evidence brief and expressed significant concerns regarding the included focus group summaries and brought this to their directors' attention. At that time, the director contacted the researchers and indicated that they did not intend to move forward with the planned stakeholder dialogue. In follow-up conversations between the supervising researcher and the directors of the organization, the purpose of KM activities was clarified and the perspectives of different stakeholders were discussed. Despite these conversations, KM activities were halted due to differing expectations. See Figure 4.2 for a visual representation of which activities were completed and which were not completed as intended.

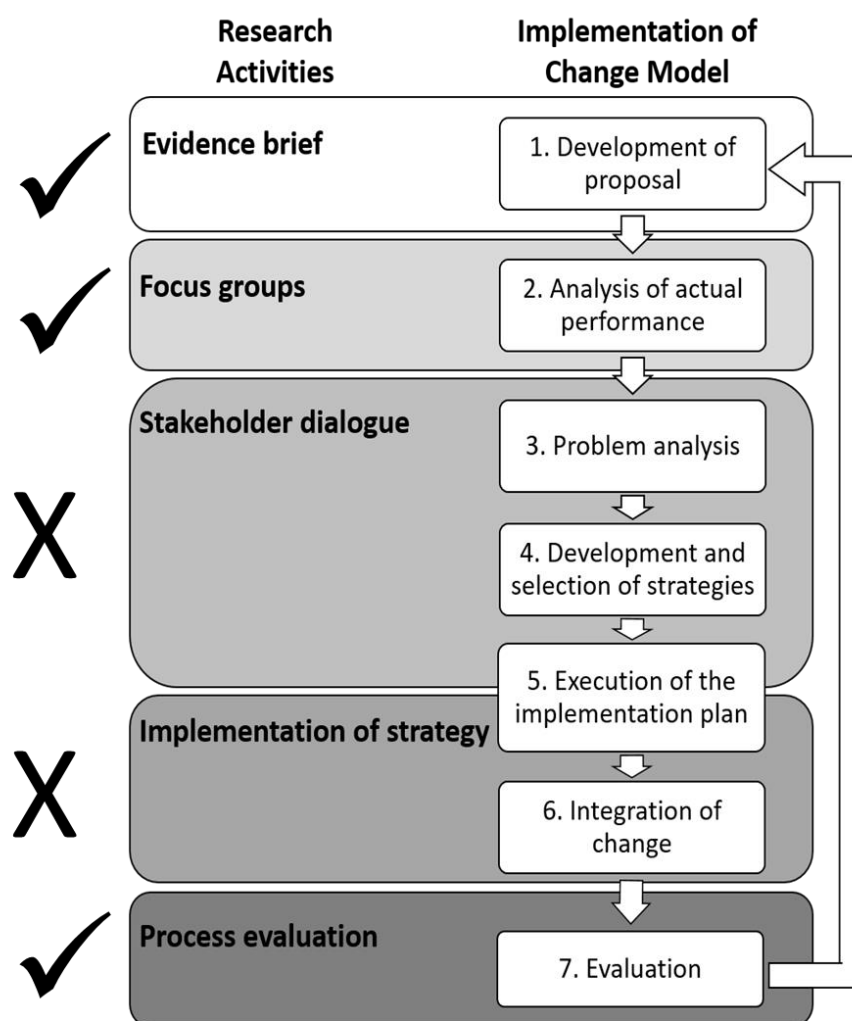


Figure 4.2. Summary of the Grol and Wensing Implementation of Change Model and actual research activities. The checkmarks indicate that activities were conducted. The Xs indicate that activities did not occur due to disruption of the KM process. Figure adapted from Grol & Wensing (2013, p. 46). Used with permission.

The content in this sub-section relates to obtaining feedback from the advisory committee regarding the evidence brief, preparing for the stakeholder dialogue, and disseminating the evidence brief to staff. To supplement our findings, we conducted a follow-up interview with the director of the community-based organization. [See Appendix E to view the protocol for the interview with the director of the organization.] The data from this interview provided a deeper

understanding of the factors that contributed to the success and disruption of the KM activities and included recommendations for engaging in KM with community-based organizations.

A) Knowledge. Overall, lack of high quality and recent research was a barrier to KM. In conversations between the supervising researcher and the director of the organization, the director indicated that the organization's values did not align with some strategies. Unfortunately, the researchers had minimal evidence to support the strategies, given that they had not been extensively evaluated.

B) Commitment and consistency. After the focus groups had been conducted, the advisory committee members appeared less engaged than they had been previously. This corresponded with a reduction in the number of individuals on the advisory committee. As mentioned previously, after six months of working with the advisory committee, there were two remaining advisory committee members, one of whom was an original member. Although the remaining members continued to attend meetings, email communication indicated that they were less responsive to emails from the primary researcher and advisory committee minutes indicate that they did not provide detailed feedback regarding the evidence brief content. Furthermore, during a follow-up interview, the director confirmed that the advisory committee did not distribute the evidence brief to other participating staff members prior to the stakeholder dialogue. Findings indicated that the directors' and advisory members' engagement declined over the course of the KM process.

C) Communication. Based on the discussions between the supervising researcher and the director of the organization, it was evident that when preparing for the stakeholder dialogue, important email correspondence was overlooked by advisory committee members.

Although a meeting was held to obtain feedback regarding the evidence brief content, the advisory committee members provided very few suggestions. The researcher then emailed an updated version of the evidence brief, which was to be reviewed by the advisory committee. However, this email was accidentally overlooked and the evidence brief was not reviewed until three days prior to the scheduled stakeholder dialogue, when concerns were expressed to the researchers. In the follow-up interview, the director of the organization indicated that they perceived the focus group summaries included in the evidence brief to be negative and focusing too much on the aspects of existing supports that were ineffective. The director suggested that it would have been more useful if the focus groups discussed examples of current practices and programs that were effective.

Director: ...maybe the questions needed to be more from an appreciative inquiry lens. So instead of I'm getting the focus group participants focused on what's not working like maybe focused on examples of when things are working at their best and really trying to understand what goes in to making it work instead of getting kind of bogged down and- and why things aren't working...

However, the advisory committee members did not provide this feedback to the researcher ahead of time and had previously approved the final focus group protocol and the way in which questions were worded. During the follow-up interview with the director, it became clear that the director was unaware of the content of the focus group protocol.

Researcher: [...] the advisory committee supported me in making decisions regarding the questions that we were asking at the focus groups. So they reviewed the protocols and gave me suggestions on wording or if we should ask different questions or anything like

that. I'm wondering if these decisions and the findings of the consultations [were] report[ed] to you and [other director] during that time?

Director: [...] as far as when the focus groups got started, there was no, there was nothing that was brought back that they had ear-marked as something that they were concerned about.

Researcher: [...] what I'm hearing is that the exact questions we were asking in the protocol uh it doesn't sound like you- you got to see those?

Director: Nope.

Lack of detailed communication amongst the researchers and advisory committee members with the director of the organization likely contributed to their dissatisfaction with the focus group questions and associated summaries that were included in the evidence brief.

Step 6 – Implementing a Friendship Support Strategy

To integrate an implementation plan into the organization's practices, we had intended to support service-providers to implement change over a 6-month period. This step was not conducted for the aforementioned reasons.

Step 7 – Evaluation

To evaluate the KM process, we collected data throughout each step. We analyzed advisory committee meeting minutes and focus group transcripts. We also wrote and reviewed research memos written throughout the KM activities. Given that the stakeholder dialogue and implementation phase did not occur, we did not have a stakeholder dialogue transcript, questionnaires, or implementation team minutes to analyze. Therefore, in addition to the

intended activities, we conducted a follow-up phone interview with the director of the agency and we qualitatively analyzed the transcript of that interview.

Discussion

The aim of this project was to conduct a process evaluation of KM activities in the context of an organization providing community-based supports to persons with ID, and provide practical recommendations to inform KM practices. We completed Steps 1, 2 and part of Step 3 of the Grol & Wensing Model (2013), by creating an advisory committee, developing an evidence brief, and conducting focus groups with service-users and caregivers. However, prior to completing Step 3, the community-based organization withdrew and we did not conduct a stakeholder dialogue and implement changes within the organization. Instead, we conducted a follow-up interview with the director of the organization to seek their perspective on the facilitators and barriers to KM.

The advisory committee consisted of service-providers at a community-based organization, whom we had bi-monthly meetings with and engaged in frequent email communication with over the period of eight months. Discussions and decisions focused on tailoring activities to maximize accessibility for service-users and caregivers, and to align with the organization's values and capacities. During the focus groups with service-users with ID and caregivers, we obtained their perspective on their current friendship supports, additional friendship support needs, and feedback for implementing friendship support strategies. In the follow-up interview with the director of the organization, we obtained their perspective regarding the disruption in the KM process and suggestions for improving future KM activities.

Knowledge, Commitment and Consistency, and Communication were the three overarching themes that we identified through the process evaluation. We discussed how these aspects acted as facilitators or barriers at each step of the KM process. By understanding how these factors facilitate and hinder KM at different steps of the process, we have developed suggestions for conducting KM with community-based organizations.

Implications

Terms of Reference.

Lack of a clear structure and roles likely contributed to a decline in commitment of and communication with advisory committee members, as this is a key aspect of successful implementation of change (Grol, Ouwens, & Wollersheim, 2013). At the outset, advisory committee members' apparent motivation was initially sufficient to carry the KM process forward. However, when developing the evidence brief, communication and commitment to KM activities likely would have been improved if the advisory committee members had been assigned specific roles with regard to contributing to the content. Clearer terms of reference (e.g., Department of Education and Early Childhood Development, 2019) would have helped identify who was accountable for the different activities that needed to occur; the evidence brief could then have been written in a manner that aligned better with the organization's perspective (Grol & Wensing, 2013).

Upon partnering with an organization, we recommend that researchers, the director of the organization, and the advisory committee all contribute to the development of clear terms of reference that explicitly outline each individual's roles and associated tasks, as well as project timelines. Additionally, a comprehensive plan should be created in case an advisory committee member has to leave the team (e.g., replace the individual, update the new team member, ensure

they understand their role, etc.). Furthermore, after team meetings, we suggest explicitly outlining each person's duties and asking them to approve or sign off on the minutes. By providing clear expectations, it is anticipated that stakeholders would be more accountable. However, it is important to remember that this may be an overly prescribed method when working within a community-based organization where staff tend to take on multiple roles and have varying availability. If stakeholders are not adhering to the initially agreed upon terms of reference, it will be crucial to collaborate with them ongoing, regarding how best to adapt and implement a governance structure and facilitate engagement.

Engagement of Stakeholders.

It is important to engage stakeholders throughout the KM process. The lack of directors' knowledge about the KM activities we conducted (e.g., focus group questions) likely contributed to the breakdown of the KM process. Indeed, absence of sustained input from management is a barrier to successful KM (Kersten et al., 2018). Although an informal front-line leader quickly emerged on our advisory committee, there was also clearly need for the director's involvement (Dückers et al., 2009; Grol et al., 2013). When conducting KM in community-based organizations, it is crucial to clearly explain the importance of the ongoing involvement of the director of the organization, and actively engage them throughout the KM process. Recognizing that directors of non-for-profit agencies may have limited time to commit to KM activities and may prefer to delegate the work to their staff, ensure that they understand the need for them to be kept up-to-date regarding KM activities, decisions, and findings. They should review and sign-off on all meeting minutes. Additionally, periodic meetings (i.e., less frequent than the advisory team meetings) should be scheduled with the director, the lead advisory team member, and the primary researcher to discuss any concerns that arise or any additional suggestions that the

director may have.

Research suggests that rather than selecting individuals who hold the most relevant job titles, advisory committee members should be selected based on their abilities, personality, and motivation to participate (Davies et al., 2015; Kersten et al., 2018). However, it is unclear how these characteristics would be assessed, and how feasible and ethical it would be to evaluate these qualities and include and exclude people based on them. Another challenge we came up against with regard to these recommendations is that, within the context of a small organization, we had to rely on who was available and agreed to participate on the advisory committee. It is possible that not all advisory committee members were enthusiastic to participate in KM activities, and some may have viewed it as an obligation. Therefore, it is important to understand the perspectives of advisory committee members with regard to KM activities, and ensure that these are adequately addressed. Additionally, high turnover of staff is common for direct support workers of individuals with ID (Bogenschutz, Nord, & Hewitt, 2015). This likely contributes to breakdowns in commitment and consistency throughout the KM process, especially given the amount of time KM and implementation of change require. When engaging in KM within a community-based organization, it will be essential to monitor employee turnover and actively address with the team how this affects KM activities and engagement of stakeholders.

Methods of Communication.

Methods of communication should be adapted for the type of information being conveyed. Communication via emails and meetings has been identified as a facilitator to KM (Kersten et al., 2018). However, the findings from this study suggest that it depends on the type of information being conveyed. Emails were beneficial for communicating quick logistical information, but not detailed feedback. Lack of meetings has been identified as a barrier (Kersten

et al., 2018). When the advisory committee did not provide detailed feedback regarding the evidence brief during a team meeting or via email, this lack of feedback (and reasons why) should have been addressed in person by the researchers, and an additional team meeting should have been scheduled so that the advisory committee could provide detailed feedback. It is important for individuals conducting KM to be aware of how responsive stakeholders are, as this can be a good indicator of their engagement. If one notices a reduction in communication, they should address it and problem solve regarding how to effectively move the KM process forward.

Limitations

Overall, lack of high quality and recent research on friendship supports for adults with ID was a barrier to KM. In retrospect, it would likely have been useful to review literature on friendship strategies in other populations who experience social isolation, such as with individuals who are elderly or experience mentally illness (Medvene et al., 2016; Sheridan et al., 2015). Having higher quality research on friendship facilitation would have bolstered the evidence brief and provided the researchers with stronger support for implementing these strategies within the organization.

There are inherent challenges to conducting KM within a community-based setting, which likely contributed to the termination of this project. Staff tended to have limited time and resources to dedicate to KM activities in addition to their primary roles at the organization. These challenges, as well as high employee turnover, likely led to less engagement and consistent communication between stakeholders. Although this project was a case study, i.e., the KM process was conducted within the context of an organization that supports individuals with ID, our findings are likely relevant to conducting KM within other community-based settings, but they should be adapted to the context of the participating organizations. For example, it would be

important to consider service-users knowledge, abilities, and motivation prior to adapting or implementing practice changes.

Future Directions

There is currently a paucity of research on KM in community-based settings. As such, there is a need to explore certain aspects of KM that may be unique to the community sector and the provision of social services. One such area is regarding how to analyze the local context (Davies et al., 2015). Given the importance of using practical and experiential knowledge to facilitate practice change, it is important to understand the unique local context in which KM is taking place. This can be done by assessing facilitators and barriers to practice change, which affect the success and disruption of the KM process (Davies et al., 2015; Harrison, Legare, Graham, & Fervers, 2010). Although KM theories recommend analyzing barriers and facilitators to KM, there is no single method for carrying this analysis out. However, given that service-providers in a community-based organization will be the primary agents of change (i.e., ultimately, they will implement the strategy), it is important to understand their perspective. By systematically evaluating KM processes across different community-based settings, we can identify practical recommendations that can inform existing KM models.

Conclusion

There are a number of KM and implementation of change models (Graham & Tetroe, 2009; Grol, Wensing, Bosch, Hulscher, & Eccles, 2013). However, most of these models are theoretical and present the ideal scenario for moving research into practice. Furthermore, recommendations are broad and can be difficult to adapt to unique settings (Davies et al., 2015). Given that KM is a complex process that is challenging to sustain, it is important that models are informed by applied research. We presented findings from a KM process that was disrupted,

discuss warning signs that may signal an upcoming disruption, and provide recommendations for overcoming these challenges. This information can be used to inform KM endeavours in community-based settings with limited budgets and few available staff. Additionally, other forms of research can inform KM in these contexts. For example, obtaining feedback from stakeholders associated with community-based organizations can lead to implementation of more contextually relevant KM activities within these settings [see Chapter 5 for an example of this type of research].

**Chapter 5: Service-Provider Perspectives on Knowledge Mobilization Methods in
Community-Based Services Supporting Adults with Intellectual Disabilities: Post-Test
Surveys and Interviews**

Fulford, C., & Cobigo, V. (Accepted 2020, April). Service-provider perspectives on knowledge mobilization methods in community-based services supporting adults with intellectual disabilities: Post-test surveys and interviews. *Canadian Journal of Community Mental Health*.

Contribution

Author Contributions

Casey Fulford, the primary author, conducted data collection with the service-organization, conducted data analysis, and wrote the majority of the paper content.

Dr. Virginie Cobigo, the supervising author, facilitated recruitment, supported data collection, and met with Ms. Fulford frequently to discuss the research questions, data collection, and data analysis. Throughout the process, Dr. Cobigo provided guidance and recommendations regarding article content and edited the full paper.

Acknowledgements

I appreciate the support provided by the Multidimensional Assessment of Providers and Systems (MAPS) research team, including Drs. H  l  ne Ouellette-Kuntz, Lynn Martin, Rosemary Lysaght, and my supervisor, Dr. Cobigo. They facilitated my data collection by distributing recruitment material through the MAPS network. I am also grateful to Patricia Lamarche at Valor & Solutions for distributing recruitment material to their networks, as well as organizing and hosting my online presentations. I would also like to thank the service-providers that answered my questionnaires and participated in interviews regarding knowledge sharing activities.

Funding

There was no funding provided for the completion of this paper

Preamble

In Chapter 4, the knowledge mobilization (KM) process, within the context of a community-based organization that supports adults with intellectual disabilities (ID), was terminated prior to dissemination of the evidence brief. The activities described in the current chapter were conducted as a follow-up to Chapter 4, after the original intended research activities that aligned with the Grol and Wensing Implementation of Change Model (2013) had been halted. During the study described in Chapter 4, we collaborated with an advisory committee, obtained the perspectives of service-users and caregivers, and conducted an interview with the director of the organization, but we were unable to seek knowledge from service-providers, as we had intended. Therefore, for the current study we explored the perspectives of service-providers in different community-based organizations regarding KM activities. We disseminated the content from a de-identified version of the evidence brief (i.e., it did not contain information about the original community-based organization's practices) to service-providers and obtained their feedback regarding how knowledge was shared and exchanged, and what content would be most valuable to them when considering adapting friendship support practices in their organizations.

Abstract

Evaluation of knowledge mobilization (KM) activities in community-based mental health and social service organizations is needed. Our objective was to understand how service-providers want to access and share knowledge, to improve KM practices to better support adults with intellectual disabilities (ID). We distributed information about five strategies for supporting friendships; this included strategy descriptions, outcomes of strategy evaluations, and practical implementation considerations. This information was distributed 1) at a conference workshop for service-providers that support individuals with ID, 2) through online modules that were sent to an electronic communication network of stakeholders interested in accessing research evidence to improve social inclusion for individuals with ID, and 3) via online workshops directed towards members of an electronic network that provided professional training to individuals who support persons with ID. Service-providers who received the information on friendship support strategies were asked to complete questionnaires and phone interviews regarding the format and content of the material. Service-providers recommended that knowledge be disseminated across multiple formats. They emphasized the importance of sharing a variety of types of information, including research knowledge, practice-based knowledge informed by workers' experiences, and experiential knowledge of service-users. Finally, they highlighted the importance of adapting KM activities to the context of the organization, because they will be affected by factors such as the focus of services, available resources, and service-user characteristics. The findings highlight the complex nature of KM in community-based services and the importance of adapting the KM process to the local organization.

Introduction

Over the past four decades, within the mental health and social services fields, there have been increasing rates of scientific publications focused on knowledge mobilization (KM) to facilitate improvements in policy and practice (Goldner et al., 2011). There is greater recognition of the importance of knowledge exchange and shared decision-making amongst a variety of stakeholders (e.g., service-users, family members, service-providers, policy makers, researchers), in addition to using scientific knowledge to inform change (Goldner et al., 2011). KM is a process that connects researchers, practitioners, and stakeholders who have experiential knowledge (Bennet et al., 2007). It involves the multi-directional flow of knowledge between stakeholders to achieve social impact, and can lead to improvements in policy and practice (Abma et al., 2017; Government of Canada, 2012).

KM entails a number of activities, including knowledge dissemination and exchange (Government of Canada, 2012). Knowledge dissemination refers to the intentional communication of key findings to relevant stakeholders, in a user-friendly manner (Government of Canada, 2010). Knowledge exchange refers to co-learning that occurs when stakeholders collaborate and share knowledge (Government of Canada, 2016). There is a need to evaluate KM in community-based settings to develop more effective strategies, as it is understudied in these settings (Hardwick, Anderson, & Cooper, 2015).

Community-based organizations are a crucial resource for facilitating friendships for adults with intellectual disabilities (ID), which is important because high quality friendships are associated with better quality of life outcomes (Friedman & Rizzolo, 2018). Service-providers who support individuals with ID play a central role in KM efforts (Kersten, Taminiau, Schuurman, Weggeman, & Embregts, 2018). They are often knowledgeable about the

community's needs and understand how to work effectively with community members (Shooshtari et al., 2014). However, both clinicians and family members that support individuals with ID have indicated that lack of access to research is a barrier to KM (Kersten et al., 2018; Shooshtari et al., 2014). Service-providers have also indicated that they require more user-friendly research outputs and stronger relationships with researchers to better support individuals with ID (Shooshtari et al., 2014). These findings highlight the need for effective dissemination efforts to foster KM and ultimately improve supports for individuals with ID.

Our research objective was to understand how service-providers at community-based organizations wanted to access and exchange knowledge, in order to improve KM practices to support friendships for adults with ID. We sought to answer three research questions: 1) What knowledge (i.e., scientific, practice-based, experiential) should be disseminated to service-providers? 2) How should knowledge be disseminated and exchanged with service-providers? and 3) What factors need to be considered when exchanging knowledge with and adapting knowledge for service-providers in different contexts?

Method

Context

This study took place within the context of a larger project on assessing knowledge mobilization activities in community-based services that support adults with ID. Given that friendship support tends to be important to stakeholders associated with these services, we decided that KM activities would focus on knowledge on friendship support practices. Therefore, prior to engaging in the methods outlined below, we conducted a systematic literature review of friendship support strategies for adults with ID [see Chapter 4]. We then partnered with a community-based organization that supports adults with ID. We conducted focus groups with

their service-users with ID and family caregivers to gain their perspectives on the reviewed strategies and discuss implementation considerations [see Chapter 5]. The literature review and focus groups were conducted to gather information on friendship support strategies that could then be used to inform implementation of practices within community-based settings. We used these findings to develop an evidence brief, which is a report that summarizes the best available research on a given topic to inform decisions (e.g., related to friendship support practices) among key stakeholders (The SURE Collaboration, 2011). The evidence brief included summaries of the reviewed strategies and focus group findings, as well as implementation considerations. [See Appendix D to view the de-identified evidence brief]. The content included in the evidence brief was used to develop a conference workshop, online presentation, and online information modules about different strategies for supporting friendships for adults with ID.

Ethics

Ethics approval was obtained from the Research Ethics Board at the University of Ottawa prior to beginning data collection.

Research Design

The research design was a quasi-experimental post-test only study. We sought to understand how service-providers viewed the utility and relevance of different professional intervention formats for the purposes of knowledge sharing and exchange. This was done within the context of sharing knowledge on friendship support strategies for adults with ID. We did not pre-test and post-test service-users' knowledge on friendship support strategies, as we were not examining if one distribution method was more effective at teaching service-providers.

Participant Recruitment

Phase 1 – Questionnaires. We recruited participants through three professional intervention methods for effecting change (Grol, Bosch, & Wensing, 2013). The three methods included a conference workshop, online distribution of educational modules, and an online workshop, all directed toward service-providers who support adults with ID. We summarized the content from the evidence brief, and used these summaries to convey the same information across all three formats. Specifically, we discussed the reviewed friendship support strategies for adults with ID, presented the perspectives of adults with ID and family caregivers regarding these strategies, and discussed factors that should be considered when community-based organizations adapt and/or implement friendship strategies to support their service-users.

Conference workshop. In April 2018, the authors presented a workshop at a provincial conference. [See Appendix F to view the workshop slides.] The formal PowerPoint presentation lasted 45 minutes and was followed by 30 minutes of discussion. After the workshop, we provided consent forms and paper questionnaires that included questions about the workshop. Approximately 40 individuals attended the workshop and 25 completed the questionnaires ($N = 25$).

Online distribution of educational modules. In June 2018, a newsletter was sent to individuals who were part of an electronic communication network that was developed by researchers who aim to provide research evidence to improve social inclusion for individuals with ID (Multidimensional Assessment of Providers and Systems, 2016). Recipients primarily included service-providers who work at community-based organizations within Ontario. The newsletter contained a link to online educational modules. [See Appendix G to obtain the link to the educational modules.] The modules were developed using Articulate Rise 360, a software for developing online courses (Articulate, 2019). The online course consisted of 12 modules and

altogether took approximately 30 minutes to read. The newsletter and the educational modules contained a link to a consent form and questionnaire about the modules. The electronic newsletter was sent to 388 individuals, of those individuals 153 people opened the email, 16 of whom opened the link to the modules, and one person ultimately completed the questionnaire ($n = 1$).

In September 2018, the recruitment information was sent out again. However, this time it was the only content included in the email; it was not part of a broader newsletter, which was the case in the previous mail out. The email was sent to 378 individuals, of those individuals 155 people opened the email, of those 33 people opened the link to the English information modules, and ultimately 19 people completed the English questionnaire ($n = 19$, $N = 20$). A link to French educational modules was also included in with the second wave of the English recruitment material (note: this was not included in the first wave). [See Appendix G to obtain the link to the French educational modules.] Out of the same 155 people that opened the email in the, three individuals opened the link to the French modules, and none of them completed the questionnaire ($n = 0$). Across the two waves, 20 individuals completed the English questionnaire and none completed the French questionnaire ($N = 20$).

Online workshop. In August 2018, an advertisement for a French online workshop was sent through subscribers to a network that provides professional training to individuals that support persons with ID (Valor & Solutions, 2017). The advertisement was electronically sent to 1700 individuals and 260 of them opened the email. The information was again distributed to the same 1700 people in September 2016, and at that time 314 individuals opened the advertisement. Ultimately, individuals from 10 organizations that support individuals with ID attended the French workshop. We cannot report exact numbers of participants attending, as organizations did

not indicate the number of employees attending the workshop. The workshop was 45 minutes in length and was presented in the format of a webinar; participants could see and hear the presenter, while viewing PowerPoint slides, and had the opportunity to verbally ask questions after the formal presentation. [See Appendix H.1 to view the presentation.] At the end of the workshop, we provided a link to the consent form and online questionnaire about the workshop. No attendees completed the French questionnaire ($n = 0$).

In October 2018, an advertisement for an English version of the online workshop was sent to 100 service-providers. Recipients were encouraged to forward this advertisement to their colleagues and networks. Ultimately, service-providers from eight organizations attended the English workshop, which was presented in the same format as the French workshop described above. [See Appendix H.2 to view the English presentation.] Two individuals completed the English online workshop questionnaire ($N = 2$).

Overall, 47 individuals participated in Phase 1. See Table 5.1 for a breakdown of the number of individuals participating across the different distribution formats. Although it was possible that service-providers could have been recruited through multiple distribution formats, review of demographic information indicates that no individuals responded to the questionnaire multiple times, and all 47 respondents were unique individuals.

Phase 2 – Interviews. At the end of the questionnaire, participants were asked if they were interested in participating in a semi-structured follow-up phone interview. Nineteen expressed interest. They were all invited to participate in a phone interview. Ultimately, six individuals participated in Phase 2 of the study; two individuals from the conference workshop, three from the online modules, and one from the online workshop participated in phase 2 ($N = 6$).

Table 5.1. *Participant Numbers across Distribution Formats for both Phases*

	Phase 1 (N = 47)	Phase 2 (N = 6)
Conference Workshop	<i>n</i> = 25	<i>n</i> = 2
Online Modules	<i>n</i> = 20	<i>n</i> = 3
Online Workshop	<i>n</i> = 2	<i>n</i> = 1

Participant Demographics

The majority of participants who completed Phase 1 (*n* = 43) and all participants who completed Phase 2 (*n* = 6) worked in Ontario, Canada. Participant demographic information for both phases are included in Table 5.2. Table 5.3 provides detailed demographic information for each participant that participated in Phase 2.

Table 5.2. *Participant Demographics*

Demographics	Phase 1 (N = 47)	Phase 2 (N = 6)
Age	<i>M</i> = 42.03 (<i>SD</i> = 13.34)	<i>M</i> = 38.00 (<i>SD</i> = 15.22)
Job Position	Director/Manager = 32% Direct Support Staff = 15% Clinician = 15% Case Manager/Worker = 17% Other = 15% No Answer = 6%	Director/Manager = 16.75% Direct Support Staff = 16.75% Clinician = 16.75% Case Manager/Worker = 16.75% Other = 16.75% No Answer = 16.75%
Years in ID field	<i>M</i> = 16.14 (<i>SD</i> = 11.03)	<i>M</i> = 11.50 (<i>SD</i> = 12.01)

Table 5.3. *Breakdown of Phase 2 (Interview) Participant Demographics and Intervention Methods*

Pseudonym	Age	Job Position	Years in ID field	Intervention Method
Jordan	No Answer	Other (Developmental Services)	10	Conference workshop
Kira	27	Direct Support staff	2	Conference workshop
Sarah	28	Director/Manager	5	Online modules
Manuela	42	Case Manager/Worker	8	Online modules
Danielle	63	No Answer	35	Online modules
Zara	30	Clinician	10	Online workshop

*Note*¹ The names used in this table are pseudonyms.

Materials

Phase 1 – Questionnaires. The questionnaires included questions regarding basic demographics, the utility of the content presented, clarity of the format, improving content, and preferred distribution methods. They consisted of multiple choice, five-point Likert-scale questions, and open-ended questions. [See Appendix I to view the French and English versions of the questionnaire that was administered after each distribution method].

Phase 2 – Interviews. Semi-structured phone interviews lasted approximately half an hour and were audio-recorded. The focus of the interviews was to understand how service-providers at community-based organizations can use research knowledge to adapt practices. Unique follow-up questions were asked to participants based on their responses to open-ended items on the questionnaire. We then asked questions about the factors that participants thought had the biggest impact on how the information presented in Phase 1 was perceived by other

service-providers. We transcribed each audio-recording. [See Appendix J for a copy of the interview protocol.]

Analysis

Phase 1 – Questionnaires. Frequencies for Likert-scale questions were calculated. Qualitative thematic analysis was used to identify recurring responses to open-ended questions (Riger & Sigurvinsdottir, 2015). We first used deductive methods; we developed an a priori coding structure based on the research questions and applied it to the data. We then used inductive methods, by flexibly adapting the coding structure to reflect participant responses (Braun & Clarke, 2006; Miles, Huberman, & Saldana, 2013). This consisted of an iterative process to cluster related ideas together to identify themes relevant to each research question. The primary author and a research assistant met regularly to review and adapt the coding structure. Summaries of the clustered responses relevant to each research question are presented.

Phase 2 – Interviews. We imported all interview transcripts into QSR NVivo 11, which was used to organize the data and facilitate analysis. We conducted a qualitative thematic analysis of the data to identify recurring ideas (Riger & Sigurvinsdottir, 2015). First cycle coding consisted of deductive and inductive analysis (Miles et al., 2013). We reviewed all raw data and developed a list of deductive (i.e., a priori) codes (Braun & Clarke, 2006; Miles et al., 2013), informed by the research questions. We then conducted inductive coding; we used the a priori list of codes and revised the list to better fit the data as needed (Braun & Clarke, 2006; Miles et al., 2013). During second cycle coding, we used an iterative process to cluster related codes to identify the main themes. The primary author wrote analytic memos throughout data analysis to facilitate data synthesis and theme identification (Miles et al., 2013). The authors reviewed and adapted the coding structure to better fit the data.

Findings

Research Question 1: What knowledge should be disseminated?

Figures 5.1 and 5.2 present data from the questionnaire items regarding the content that we distributed and include response frequencies.

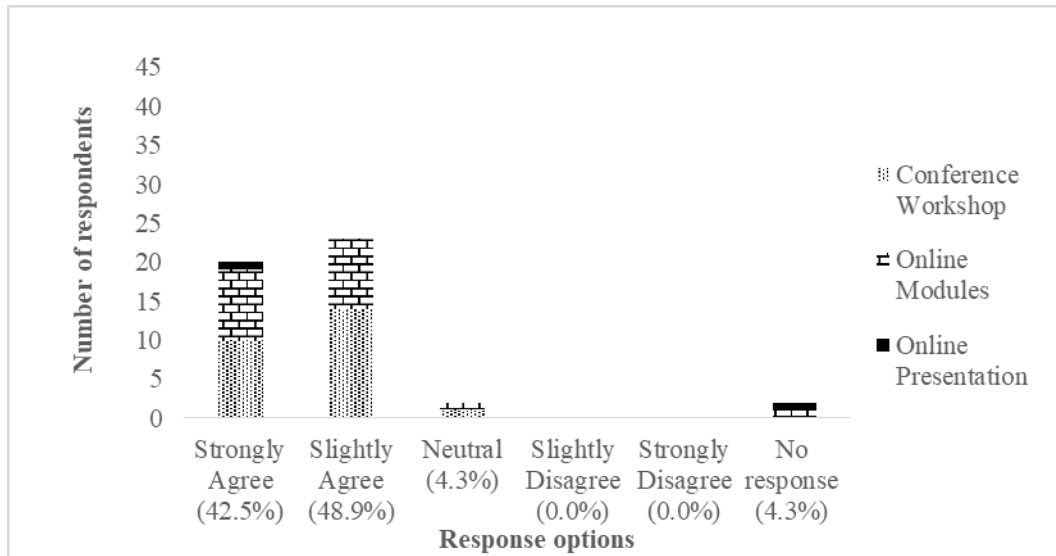


Figure 5.1. Service-provider responses to the statement "The content could be used to adapt practices", categorized by recruitment method.

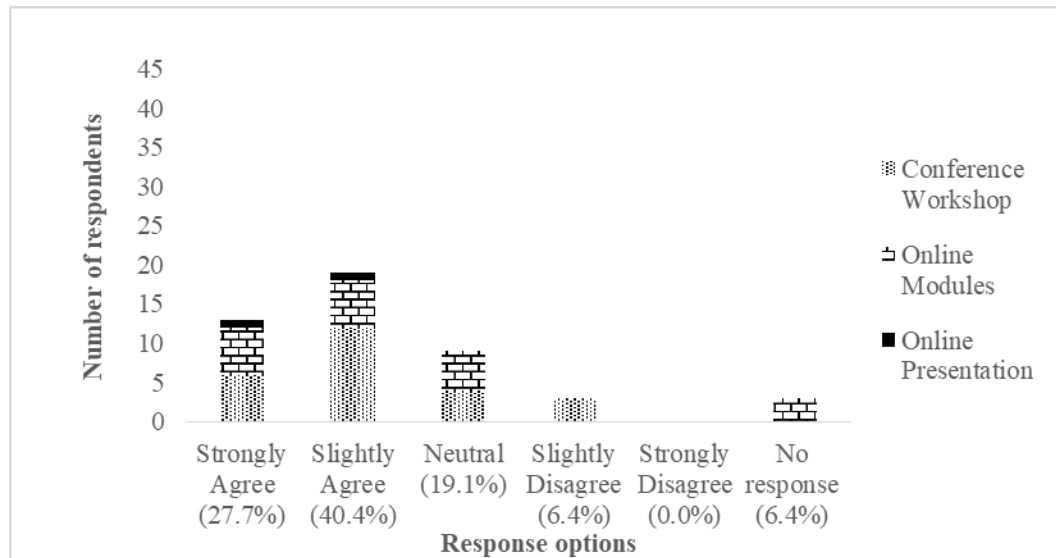


Figure 5.2. Service-provider responses to the statement "The content included new information regarding support strategies", categorized by recruitment method.

Phase 1 – questionnaires. The majority of service-providers indicated that the information provided (i.e., descriptions of researched strategies, outcomes, views of service-users and family caregivers regarding these strategies, and implementation considerations) would be useful for adapting practices within their organizations (see Figure 5.1). In response to the open-ended questions about how the content could be used to change practices, service-providers indicated that the information led them to reflect on the importance of the topic and stimulated ideas on how to support service-users. Furthermore, they noted that the information could be used within their organizations to emphasize the importance of specific services, facilitate discussions regarding practices, adapt existing practices, and implement new strategies.

The majority of individuals also indicated that the content provided new information relevant to supporting their service-users (see Figure 5.2). Some service-providers stated that they were previously unaware that friendship support was being studied, and the content we distributed provided that knowledge. Other service-providers indicated that the content we distributed included strategies that they were not previously aware of, and it highlighted that there are a number of ways to support friendships for adults with ID, across a variety of environments. They also noted that the data that we presented fostered a better understanding of the existing friendship support strategies that are and are not effective, and the benefits and challenges associated with each strategy. The service-providers who were already aware of the strategies we presented noted that the content included more details on strategies that they were only broadly aware of. Furthermore, they indicated that the views of adults with ID and family caregivers provided new perspectives. Despite most service-providers indicating that the presentation included new information, they also indicated that they would require more practical information in order to effectively implement strategies.

Service-providers said they would require more details regarding the strategy components and they also indicated they would need information on how to adapt existing interventions to their organization. They also wanted to be presented with more detailed research data from the original studies, as well as data from case and site studies. Service-providers expressed a desire for more practical knowledge from other service-providers who had experience implementing the strategies. Finally, they noted that a more personal element, such as videos and quotes from caregivers and service-users (i.e. experiential knowledge) would be appreciated.

Phase 2 – interviews. In the follow-up interviews, service-providers elaborated on the importance of including experiential knowledge.

Zara (clinician, online presentation): I find that people integrate knowledge best when there's a lot of personally relevant examples and I think you really try to highlight using the words [that] people have given you about what works and what didn't work.

Service-providers also indicated the importance of having concrete examples on how to implement researched strategies.

Danielle (no job position specified, online modules): it's important that anything that's out there [research findings] be transformed into something that's more understandable, but it needs concrete examples.

Research Question 2: How should knowledge be disseminated and exchanged?

Figures 5.3 and 5.4 present data from the questionnaire items regarding the formats we used to distribute information on friendship supports, and include response frequencies according to distribution method.

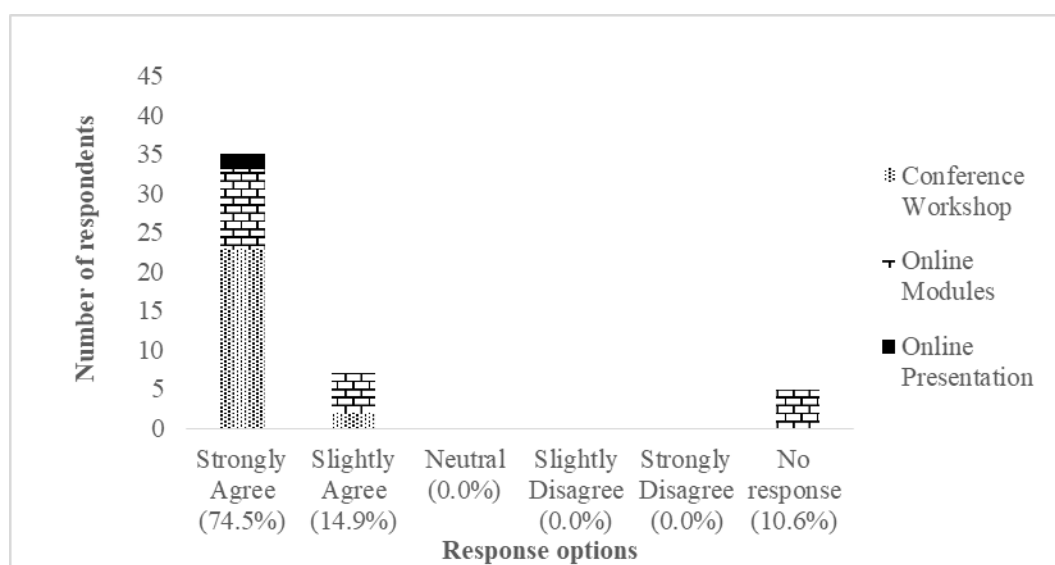


Figure 5.3. Service-provider responses to the statement "The format was clear and easy to understand", categorized by recruitment method.

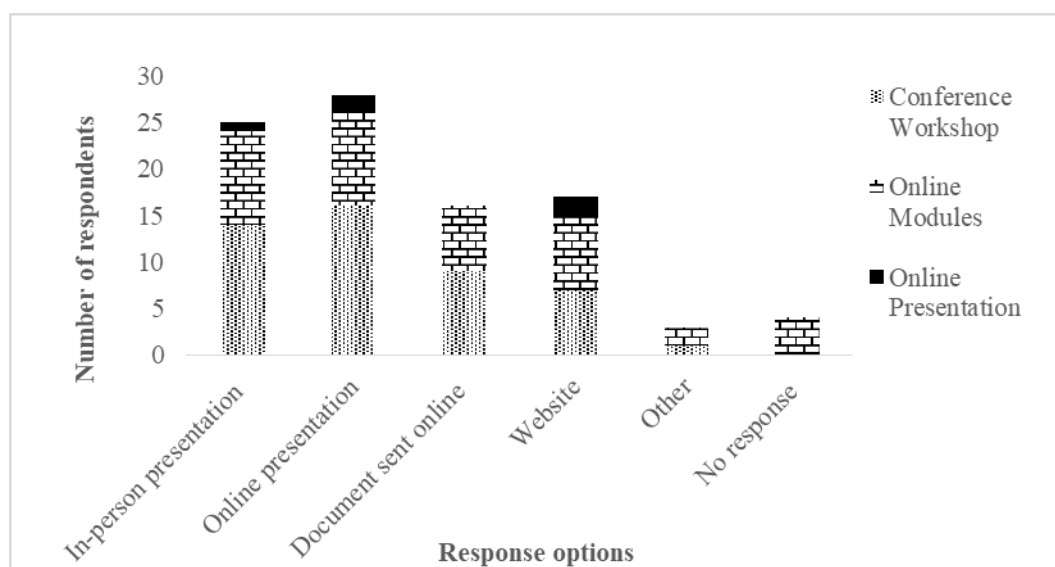


Figure 5.4. Service-provider responses to the statement "What would be the most useful format for distributing the content?", categorized by recruitment method."

Note¹. Respondents could select multiple options.

Phase 1 – questionnaires. See Figure 5.4 for service-provider views about the format in which information was distributed. The majority of service-providers indicated multiple methods

for disseminating knowledge would be beneficial. When responding to open-ended questions, service-providers highlighted the benefits and challenges of different knowledge dissemination and exchange methods. Some service-providers noted that online information modules and videoconferencing would allow people to access information from different locations and at different times, making knowledge more accessible. Furthermore, they said that electronic information or documents that they could share with their colleagues would be useful. However, they indicated that these online methods do not foster exchange of ideas amongst service-providers or offer opportunities to seek clarification. During the online presentation, no service-providers asked questions, whereas in-person they were very engaged and many wanted more discussion time. They appreciated being able to share their experiences and ideas, and liked having the opportunity to seek clarification about the strategies. They also indicated that presentations that took place within their organizations would be beneficial for facilitating changes in practices.

Phase 2 – interviews. Service-providers emphasized that their interests would impact their inclination to seek out knowledge on a given topic, indicating the importance of researchers understanding service-providers' existing knowledge and interests.

Sarah (director/manager, online modules): ...your past experiences ... would definitely play a role in if you would even bother accessing the information and how you would view the information.

Jordan (developmental services worker, conference workshop): It was an interesting topic. Obviously, that's why I selected it, because I had a curiosity...

Service-providers also indicated staff roles within an organization would impact how the research knowledge would be used to adapt practices. They noted that for more wide scale changes to occur, information would need to be directed at leadership, while providing research knowledge to front-line workers could serve as more direct training.

Sarah (director/manager, online modules): It depends who is reading it. If it's someone in a leadership role, they have to turn around and think how they are going to implement the change in how things are done.

Manuela (case manager/worker, online modules): I'm just thinking of more like front line staff. They're going to be probably... focusing on the individual [service-user]...they have the direct contact with the families.

Service-providers also expressed the importance of being able to exchange research-based and practice-based knowledge through discussion in order to co-create knowledge and improve practices.

Danielle (no job position specified, online modules): It [in-person presentation and discussion] would also offer a way to understand how service-workers are figuring this out right now. So, the personal presentation gives the presenter the opportunity to hear little glitches [experienced by service-providers].

Research Question 3: What factors need to be considered when adapting knowledge and implementing it in different contexts?

Phase 1 – questionnaires. Although many service-providers thought the content was informative for changing practices, they indicated that their organizations may not have the resources (time, money, relevant knowledge) to adapt or implement strategies. Some service-providers noted that service-users have varying abilities and needs, so different strategies may be

relevant to different service-users. Finally, some noted that the focus of the strategies may be beyond the scope of their organizations.

Phase 2 – interviews.

Available research and training. It was evident that many service-providers had not received in-depth training on how to support their service-users' needs.

Kira (direct support staff, conference workshop): Most staff members are just going off of their personal experience... everyone kind of just tries to tackle it in their own way...there's nothing for us to lean back on...

Indeed, the articles identified and summarized for this study provided few concrete details on how to implement strategies. As noted above, many participants valued learning from the practice-based knowledge of other service-providers.

Organizational factors. Service-providers indicated that an organization's vision or culture would impact the way in which research knowledge is perceived.

Sarah (director/manager, online modules): The current expectations within an organization are going to colour the way that people see the new suggestions...Some will literally just walk away from it because it isn't part of the culture at that point.

In addition to the research knowledge having to align with the organization's scope of practice, resources can impact how likely a strategy is to be implemented.

Kira (direct support staff, conference workshop): ... funding is a huge thing too...How much time and research can we allocate to certain strategies? ... Everyone's is on a tight budget.

Service-user characteristics. Service-providers noted that service-users' characteristics will dictate which strategies are most relevant to supporting them.

Kira (direct support staff, conference workshop): Absolutely every single person has their strengths and weaknesses. And how you approach [supporting them] is completely different for each person.

Service-providers also indicated that the service-users' life situations will impact their ability to make use of services.

Zara (clinician, online presentation): There's kind of an implicit assumption here that the organizations that are able to implement these strategies have clients who are at a place in their life where their basic needs are met. Like they're not dealing with an immediate crisis or an immediate mental health concern or housing issue, et cetera, right?

This indicates the importance of tailoring strategies to service-users who have diverse needs and life situations. Given that not all strategies will be applicable to all service-users, service-providers suggested having a variety of strategies to choose from or combining aspects of relevant strategies, depending on service-user needs and abilities.

Kira (direct support staff, conference workshop): I think a combination approach would be [helpful]. Maybe having different options, and then picking what's best for the person.

Discussion

This paper presented the knowledge and perspectives of service-providers with regard to KM processes. Service-providers working at community-based organizations indicated that, when engaging in KM activities, it is important to exchange research knowledge, practice-based knowledge informed by workers' experiences, and experiential knowledge of service-users. Regardless of how knowledge was disseminated to them, the majority of service-providers recommended that knowledge should be disseminated using multiple formats (e.g., online and

in-person) in order to more effectively reach the target audience. They also emphasized that KM is affected by factors that are unique to each organization (e.g., focus of services, available resources, and service-user characteristics), so KM activities need to be adapted to be more contextually relevant.

Sharing Multiple Types of Knowledge

Consistent with previous findings, service-providers wanted more detailed practical information regarding how to implement the reviewed strategies (Ward, House, & Hamer, 2009). Unfortunately, many of the original articles that we reviewed, did not include details necessary to inform implementation, which commonly impedes KM activities (Hering, 2016). When we contacted the authors from the reviewed studies, we could not obtain enough detailed information to replicate all the reviewed strategies [see Chapter 5]. To facilitate KM, researchers should provide enough practical information to knowledge users, so that they can use research knowledge to adapt and implement practices.

Service-providers also noted that they could learn from others working in their field, regarding what practices have or have not been successful. Because clinicians and service-providers tend to incorporate research and practice-based knowledge into their decision making, both types of knowledge should be shared in tandem (Kislov, Wilson, & Boaden, 2017). If practice-based knowledge is not shared, knowledge users will likely be less engaged in the KM process (Kislov et al., 2017). Service-providers also emphasized the importance of hearing experiential knowledge of service-users in the form of quotes or personal stories. KM research in the mental health field indicates that when service-providers take client perspectives into account, clients are more likely to adhere to interventions (Goldner et al., 2011). Furthermore,

integrating multiple perspectives can facilitate practice changes that have a social impact and reduce power imbalances between stakeholder groups (Abma et al., 2017).

The findings from this study emphasize the importance that community-based service-providers place on exchanging multiple types of knowledge, rather than prioritizing research knowledge to inform practices. Scientific research is often not viewed as contextually relevant in community-based settings (Hardwick et al., 2015; Ungar et al., 2015). There tends to be a greater emphasis placed on experiential and practice-based knowledge, because there is less available research on community-based interventions (Owczarzak, 2012). It has been suggested that participatory action methods should be used to engage in KM with organizations that provide community-based mental health and social services, as this strategy takes into account multiple perspectives in decision making (Ungar et al., 2015). When engaging in KM with community-based organizations, it is important to emphasize knowledge sharing and stakeholder (e.g., service-users, caregivers, service-providers) collaboration in order to foster engagement of service-providers.

Formats for Dissemination and Exchange

Service-providers' roles and interests impact what information they seek out and how they use the available knowledge (Grol & Wensing, 2013), so it is important to tailor content to their needs and goals (Levac, Glegg, Camden, Rivard, & Missiuna, 2015). Participants wanted knowledge to be shared using a variety of formats. They said that online dissemination methods are more accessible, across time and location, and allow information to be more easily shared with colleagues. However, online distribution of materials is a passive approach and it does not capture the attention of all intended knowledge users (Grol & Wensing, 2013). Despite sending online newsletters and advertisements to over 2000 service-providers (although some may have

received the content in multiple formats), less than one quarter opened the emails, and far fewer read the material or attended the online presentation. This passive distribution did not appear to be effective in capturing the attention of key stakeholders who will engage in KM.

When conducting KM activities, it is crucial to engage in more targeted dissemination efforts. Because many service-providers seek out information from their peers, targeting respected and knowledgeable professionals to be opinion leaders who can disseminate information to their colleagues would be an important dissemination strategy (Grol & Wensing, 2013). Therefore, rather than passively pushing knowledge towards stakeholders, it will be important to identify key players who can facilitate KM efforts and collaborate with them regarding how to most effectively share knowledge. Additionally, dissemination efforts must involve presenting information in a variety of ways, over an extended period of time, to ensure that knowledge reaches the target audience (Grol et al., 2013; Grol & Wensing, 2013).

Service-providers recommended that knowledge exchange activities should occur in-person, as this facilitates discussion amongst stakeholders. Furthermore, active participation increases stakeholder engagement in KM (Wensing, Fluit, & Grol, 2013). Face-to-face knowledge exchange activities tend to offer more opportunities for stakeholders to interact; this allows them to better recognize whether or not shared information is being understood and accepted by others, and also offers opportunities for stakeholders to provide additional information as needed (Hwang, Singh, & Argote, 2015). This highlights the importance of knowledge sharing, rather than simply passively disseminating knowledge to stakeholders. Regardless of the dissemination method, in-person meetings with service-providers in community-based setting should be held to facilitate knowledge exchange, and discuss practical recommendations and implementation considerations for practice change.

Adapting KM Activities to the Local Context

When engaging in KM, it is crucial to consider environmental characteristics (within and outside the organization), the different stakeholders involved and how they interact with one another, and intervention characteristics (Damschroder et al., 2009). Community-based organizations have different mandates, varying resources, and service-users with different needs. Therefore, KM activities will need to be tailored to the specific community-based context (Bennet et al., 2007; Harrison, Legare, Graham, & Fervers, 2010). An intervention may need to be modified when implementing it within a setting with a smaller budget and fewer resources (Gaglio & Glasgow, 2017) or when supporting service-users who receive different amounts of funding (Davies, Powell, & Nutley, 2015). Service-providers in this study indicated that community-based organizations tend to have limited budgets and individuals with ID who access these organizations have varying amounts of funding to spend on services (Government of Ontario, 2018), both of which impact strategy implementation. Interventions or practice changes should be tailored to meet the needs and goals of affected stakeholders, which is why it is crucial to integrate research, practice-based, and experiential knowledge (Bowen & Graham, 2013; Damschroder et al., 2009).

Limitations

Given that recruitment was done sequentially, it was possible that some of the same service-providers could have been recruited through multiple formats and participated multiple times. However, based on the demographic information provided, it does not appear that any participant participated across the different dissemination methods. Due to the recruitment strategy, there were varying numbers of participants across the different dissemination methods. Specifically, there were 25 service-providers who attended the workshop, 20 who reviewed the

online modules, and two who attended the online presentation completed the questionnaire. These differences may have occurred because we used different networks to recruit participants. The individuals who made up the different networks may have had varying levels of interest in supporting friendships for adults with ID, which would highlight the importance of directing knowledge toward individuals who are invested in the subject matter. Another limitation to note is that the questions regarding service-user satisfaction with the content and format the material we distributed showed a ceiling affect, which suggests that service-users may have had a positive response bias and/or our items were not effective at capturing a range of responses. Finally, an important limitation to be aware of is that no individuals who received the content in French (online modules and online workshop) participated in the study. Attention to ethno-cultural diversity might be warranted when evaluating KM activities in the future to determine whether they should be tailored cultural preferences.

Conclusion and Future Directions

When engaging in KM with community-based organizations, it is crucial to engage in knowledge exchange and collaborate with all relevant stakeholder groups. The current paper included service-providers, but to develop more effective KM practices, future research and KM activities should also include other relevant stakeholders, such as service-users', caregivers', and volunteers'. Furthermore, when conducting KM research, it will be beneficial to examine the extent to which stakeholders were provided with new knowledge and learning. Moving forward, it will be important to identify key players who are motivated to facilitate KM efforts and collaborate with them regarding how to most effectively exchange knowledge, rather than passively pushing knowledge towards stakeholders. KM in community-based settings requires

the multidirectional flow of knowledge amongst all stakeholders, and thus, will be most effective when all parties are motivated to engage in KM activities.

SECTION 4: Discussion

In the previous sections, we provided a conceptual discussion of the principles for using knowledge to inform practice (Section 1), completed a substantive review of the current context of friendships of adults with intellectual disabilities (Section 2), and presented empirical findings from primary research evaluating knowledge mobilization activities in community-based services (Section 3). The current section includes our general discussion, in which we reflect on the previous sections of the dissertation. We present key messages based on our findings and discuss how they relate to the existing literature

Chapter 6: General Discussion

Overview of Dissertation

This dissertation was an implementation science project; the objective was to conduct an evaluation of knowledge mobilization (KM) activities in community-based services that support individuals with intellectual disabilities (ID). The aim of the project was to understand how stakeholders shared knowledge, used knowledge, and collaborated to make decisions regarding practices. We sought to understand how KM activities were implemented in community-based services involving multiple groups of stakeholders.

Chapter 1, the general introduction, included a conceptual discussion of the principles for using knowledge to inform practice. Chapter 2 was a systematic literature review that presented findings regarding how adults with ID conceptualized their interpersonal relationships, and the facilitators and barriers to developing and maintaining relationships. This chapter emphasized that although individuals with ID tended to place importance on their relationships, they experienced a number of barriers to experiencing fulfilling relationships, and often required the support of family caregivers and service providers to develop and maintain them. Chapter 3 also consisted of a systematic literature review and presented existing friendship support strategies for individuals with ID, which could be implemented in community-based organizations. The findings from this chapter highlighted the paucity of high-quality research on friendship support strategies for adults with ID. In Chapter 4, we presented findings from a natural field experiment about KM focused on friendship support strategies for adults with ID, within a community-based organization. We explored how KM activities were implemented and how stakeholders collaborated throughout the process, by consulting an advisory committee, conducting focus groups with adults with ID and caregivers, and completing an interview with the director of the

organization. By understanding how various factors (related to knowledge, communication, and commitment and consistency) facilitated and hindered KM at different steps of the process, we developed suggestions for conducting KM with community-based organizations. Because the planned research activities in Chapter 4 were not completed as intended, and we were unable to gain a thorough understanding of service-provider perspectives, we conducted follow-up KM activities with service-providers that supported adults with ID. Chapter 5 explored service-providers' perspectives regarding knowledge dissemination and exchange, and included recommendations for engaging in knowledge mobilization activities with community-based organizations. The findings from this dissertation led us to identify key lessons learned, which contribute to the literature regarding KM in community-based services and can facilitate the effectiveness of future KM endeavours.

Lesson 1: Overcoming Challenges Associated with a Paucity of High-Quality Research

A major obstacle we encountered when trying to engage in KM to support friendships for adults with ID is that there was a paucity of high-quality research on strategies related to this topic. Through our systematic literature review [Chapter 3], we only identified five friendship support strategies, none of which met criteria for the highest level of evidence (i.e., randomized-controlled trial). Other researchers have also found that despite the knowledge that strong social ties are beneficial to quality of life, literature on how to effectively support friendship development and maintenance for individuals with ID is lacking (Scott & Havercamp, 2018). Although we know that community-based services need to be structured in ways that foster opportunities for friendship development for adults (Friedman & Rizzolo, 2018; Hurd et al., 2018), focusing solely on scientific literature does not foster a strong understanding of how to do

this. Therefore, there is a need to incorporate multiple types of knowledge when engaging in KM to support friendships for adults with ID.

Lack of relevant research on interventions that can be implemented in community-based services is not specific to supports for individuals with ID. More research studying community-based interventions is needed, in addition to focusing on clinical trials, as this would be more applicable to community-based organizations (Owczarzak, 2012). In addition to there being a paucity of research on community-based interventions, our review of the literature indicated that the majority of research evaluating KM and implementation approaches continues to be conducted within clinical settings, rather than in community-based services. In part, this may be due to the lack of systematic research focusing on community-based interventions (i.e., because there is less relevant research to implement). Despite the paucity of research on community-based interventions, we believed that research on KM processes can and should still be studied in community-based settings. We drew on KM research findings and models relevant to clinical settings to inform our community-based KM activities.

When using clinical KM models to inform KM in community-based settings, it is important to be aware of the contextual differences across clinical and community-based settings. There tends to be more clinically-relevant research available, clinicians are typically explicitly trained to critically review and incorporate research into decision-making, and they tend to have access to research through the institutions they are involved with. Therefore, implementation activities applied to clinical settings tend to prioritize research knowledge. However, in community-based settings, there tends to be a paucity of scientific knowledge on community-based interventions, service-providers often do not have thorough research training,

and research is often not available or accessible. Stakeholders in community-based settings often highly value other types of knowledge (e.g., practice-based, experiential). Therefore, when conducting KM in community-based settings, one must consider how to effectively incorporate knowledge from a variety of sources.

There is no set way to integrate different types of knowledge throughout the KM process, because stakeholders have different opinions regarding the value of different knowledge sources. In Chapter 5, we shared research knowledge, along with the perspectives of family caregivers, service-users, and service-providers, with service-providers from a variety of community-based organizations. Although service-providers highly valued the experiential knowledge of service-users and family caregivers, and the practice-based knowledge of other service-providers, many of them wanted more detail regarding the research evidence on friendship support strategies and expressed a desire for additional research findings. This differs somewhat from previous findings. It has been suggested that service-providers in community-based organizations tend to prefer experiential knowledge over research knowledge (Ramanadhan & Viswanath, 2013); they prioritize the views of service-users, case study findings, details regarding effective practices that have been implemented in similar organizations, and expert opinion (Hardwick et al., 2015). Thus, in Chapter 5 our findings somewhat contradicted previous literature; service-providers highly valued research knowledge and wanted more scientific evidence. It is important to note that the service-providers who opted to participate in this research study may have valued research knowledge more than some of their colleagues who did not choose to participate. Nonetheless, it is clear that a portion of service-providers working in community-based research

highly value research knowledge. Preferences for different types of knowledge likely vary within and between stakeholder groups, and across different contexts.

Service-providers in Chapters 4 and 5 responded differently to the same research findings on friendship support strategies, suggesting that the context that research knowledge is delivered within may have impacted their perspectives. Service-providers in Chapter 5 were likely expecting a research-focused presentation that could inform their knowledge-base; in the recruitment material we stated that we would be presenting “applied research that is relevant to front-line staff and managers who offer social support to adults with intellectual disabilities”, and then we stated that we would also present stakeholder perspectives about the research. Service-providers indicated the desire for even more research findings. In this context there was no expectation that they would be using this knowledge to directly change their practices in the foreseeable future. Whereas, when we presented the same findings to the service-providers at the organization we collaborated with in Chapter 4, they were less receptive to the research content. In this context there was the expectation that research knowledge (along with practice-based and experiential knowledge) would likely be used to adapt practices within their organization in the near future. When there is an expectation that knowledge will be used to inform changes in practices, community-based service providers may not view research knowledge to be as relevant as practice-based knowledge (Owczarzak, 2012). Before conducting any KM activities, and throughout the KM process, we must be aware of stakeholders’ values and perspectives about the utility of different types of knowledge; research knowledge must be presented in a way that addresses stakeholders’ viewpoints.

In addition to being aware of the context of knowledge sharing activities, the manner in which knowledge is being shared is essential to consider. For example, when engaging in the KM process within a community-based organization [Chapter 4], we first obtained caregiver and service-user perspectives and presented these to service-providers alongside research findings. Prior to obtaining service-provider practice-based knowledge, KM activities were terminated. It is known that if practice-based knowledge (i.e., service-providers' knowledge) is not shared, knowledge users are less likely to engage in the KM process (Kislov et al., 2017). Our findings suggest that it is also important to consider when in the KM process different types of knowledge are shared. We believe that obtaining service-provider perspectives more thoroughly prior to sharing other types of knowledge with this stakeholder group would have more effectively conveyed the importance of their knowledge in shaping the implementation of strategies. Although this was not explicitly stated by service-providers [in Chapter 4], we hypothesize that the way in which we proceeded may have led them to think that their knowledge would not be adequately incorporated into decision making around strategy implementation. Therefore, we recommend obtaining knowledge from relevant stakeholder groups prior to sharing other types of knowledge with them, in order to emphasize that their expertise is integral in the KM process, which in turn can enhance their motivation to engage in KM activities.

Clearly the expectations regarding how knowledge is intended to be used and how knowledge is shared with various stakeholders will impact how it is perceived by them. We caution against assuming that stakeholders at community-based organizations do not value scientific research, and highly recommend that individuals facilitating KM in these settings acknowledge the value of a variety of types of knowledge and thoroughly consider how to best

obtain and exchange knowledge. This should be done by collaborating with an advisory group that consists of representatives from all relevant stakeholder groups when initially planning KM activities and throughout the process. By understanding stakeholder perspectives regarding different types of knowledge, we can more effectively exchange and incorporate knowledge from different sources to inform decisions and practice change.

Lesson 2: Adapting Knowledge Mobilization Practices to Community-Based Settings

An ongoing theme throughout this dissertation was the emphasis on needing to adapt KM activities to the local context within which they were being conducted. This need is well documented within the literature. Collaboration between stakeholder groups helps elucidate pertinent facilitators and barriers and informs adaptations to KM activities, which enhances effectiveness (Kersten et al., 2018; Scott & Haverkamp, 2018; Shooshtari, 2012; Shooshtari et al., 2014). However, researchers have not yet identified clear methods for how to effectively engage in KM with community-based organizations and how to systematically adapt activities to the local setting. This is an area that we also struggled with, as evidenced by the discontinuation of the KM process prior to completing all intended activities in Chapter 4. However, the feedback expressed by a variety of stakeholders in community-based organizations [Chapters 4 and 5] has contributed to a stronger understanding regarding how to more effectively obtain stakeholder perspectives and consequently adapt KM and implementation practices.

We found that the opinions of stakeholders (i.e., service-users, caregivers, and service-providers) regarding different friendship support strategies varied depending on how compatible they perceived the strategies to be with service-user interest and skills, service-provider resources, as well as organizational values and scope of practice. These findings indicate that the

perspectives of community-based stakeholders differ somewhat from those of healthcare professionals; within the healthcare sector, the source of an intervention, strength of evidence, degree to which intervention can be tailored, complexity, presentation, and cost of an intervention impact how it is perceived and implemented (Damschroder et al., 2009). The factors that impact how an intervention is viewed likely vary across stakeholder groups and across the settings within which they are being considered for implementation. Regardless, previous research suggests that practices (e.g., interventions, strategies) need to be adapted to the specific context that they will be implemented within, to enhance applicability and increase feelings of ownership by knowledge users (Harrison et al., 2010). Given that service-providers had varying reactions to the different friendship support strategies we presented, we suggest that when initially presenting or sharing existing research knowledge on different interventions, it is crucial to discuss how these strategies could be adapted to fit their specific context. This can be done by providing concrete examples of strategy adaptations. We believe this would lead to more buy-in into the KM process because stakeholders would have early opportunities to consider how interventions could be adapted based on contextual factors that are important to them. Providing examples of different ways to tailor implementation of strategies can also stimulate generation of their own ideas, leading stakeholders be more flexible when considering a variety of strategies for implementation.

Lesson 3: The Importance of Communication Methods and Content

Despite having a good pre-existing relationship with the community-based organization that we collaborated with [in Chapter 4], not all intended KM activities were completed. As mentioned in Chapter 4, there was a need for detailed terms of reference, which would identify

the roles and responsibilities of relevant stakeholders, provide guidelines regarding how to communicate and problem-solve, and outline important topics to address (e.g., stakeholder assumptions and expectations) throughout the KM process. Although we discussed the KM plan with the director of the organization and advisory committee members at initial meetings, and all parties appeared to agree with the intended activities, as KM activities proceeded it was evident that stakeholders had varying assumptions and expectations regarding the KM process. In retrospect, it would have been beneficial to engage in explicit routine check-ins to examine stakeholder expectations regarding each step of the process and then adapt activities through shared decision making. We had incorrectly assumed that discussions regarding expectations and potential adaptations to the process would occur during advisory committee meetings; upon reflection, dialogue in these meetings tended to focus on the logistics of pre-planned KM activities, rather than detailed conversations about how they could be tailored to better meet stakeholder needs. Because we did not have a formal way of obtaining and addressing stakeholder expectations at the outset of the project, we did not adequately adapt KM activities to the context of the organization we were working with.

Prior to initiating KM activities and throughout the process it is crucial to consider how to tailor communication to different stakeholder groups. Although researchers are aware that it is important to tailor content to stakeholder needs and goals (Levac, Glegg, Camden, Rivard, & Missiuna, 2015), there is no clear way to do this. Some researchers argue that personal attributes, such as intellectual ability, capacity, and learning styles should be considered, as they can vary between stakeholders and influence the way that KM activities should be carried out (Damschroder et al., 2009). We had success when using accessibility guidelines (Financial

Consumer Agency of Canada, 2018; Learning Disability Service at Leeds and York Partnership NHS Foundation Trust, 2019) to develop the research summaries that we shared with adults with ID [Chapter 4]. Additionally, individuals with varying capabilities may be able to support each other by working in teams; for example, in a participatory research study, one effective method for sharing knowledge was when team members with ID read information aloud to their peers who were unable to read (García Iriarte et al., 2014). Clearly, there is not one right way of adapting communication methods to different stakeholders. To develop effective communication, it is crucial to collaborate with advisors who represent all stakeholder groups, and foster creativity and flexibility when considering different methods of communication.

As evidenced by our findings in Chapter 5, even within one stakeholder group (i.e., service-providers), individuals may want information to be communicated in a variety of ways. Additionally, our findings from Chapter 4 suggest that the effectiveness of different communication methods will vary at different times in the KM process and for different activities (e.g., email worked for discussing logistics, but not obtaining detailed stakeholder feedback). The effectiveness of communication methods should be monitored continuously throughout the KM process and alternative methods of communication should be considered, as needed. Unfortunately, there is not one obvious method for evaluating communication methods. We encourage future individuals who initiate KM efforts to be very cognizant of the importance of methods of communication throughout the KM process, which can act as a barrier and facilitator to KM. Ongoing collaboration amongst an advisory group of stakeholders regarding preferred and effective communication methods will lead to more successful KM.

Lesson 4: A Note about Use of Language

When developing KM models relevant to community-based settings, we believe it is important to consider the use of language, as some of the terminology that is currently used elicits incorrect assumptions, or does not reflect current conceptualizations. For example, researchers continue to use the term knowledge users, which suggests that these individuals are receiving knowledge (Ward, 2017), despite KM definitions stating that these stakeholders contribute important knowledge to the KM process (Abma et al., 2017). Instead, perhaps knowledge users and researchers alike, should be referred to under one cohesive term, such as “knowledge providers”. The term knowledge providers would indicate that all stakeholders in this category contribute useful knowledge, rather than separating researchers from other stakeholders who provide different types of knowledge. Additionally, in the literature we reviewed (and in our research studies), researchers often initiated KM activities and there was no systematic term to refer to stakeholders who led KM initiatives. Referring to people who lead KM initiatives by a term such as “knowledge mobilizers” (Ward, 2017) may broaden our conceptualization regarding the types of stakeholders that can initiate and promote KM activities. Moving forward, when developing models to inform KM and when engaging in KM, knowledge providers (i.e., researchers and other stakeholders) should critically consider existing terminology in this field and provide cohesive definitions for the language that we do use.

Limitations

An overall limitation we experienced when conducting this dissertation relates to its community-based nature; community-based organizations tend to have scarce resources available for changing practices and often require the help of volunteers to provide services. This

context poses challenges when conducting KM, which requires additional staff time, motivation, and expertise, as well as additional organizational resources. Furthermore, there tends to be a paucity of research relevant to community-based interventions, which can be challenging when trying to incorporate research knowledge into new practices. Clearly there were a number of potential barriers to conducting this research simply because we were engaging in KM in community-based settings.

In addition to the inherent barriers associated with KM in community-based services, another challenge was that there was limited research to inform KM practices in these settings. Most knowledge-to-action models have been developed to inform change in practices within clinical settings, yet they are also applied to community-based settings (Kothari & Armstrong, 2011; Worton et al., 2017). This is problematic because clinical models tend to assume that implementation of evidence-based practices is the goal for knowledge users, whereas this is often not the case in community-based settings (Worton et al., 2017). KM goals and activities may differ in clinical and community-based settings for a variety of reasons. This is because there are differences in the focus of services provided, intended service outcomes, and the types of knowledge that are prioritized between these settings. Given the differences between community-based and clinical settings, KM models in clinical settings need to be adapted for use in community-based services.

The current project is a prime example of the limitations of applying a clinically-relevant KM model to community-based settings. The emphasis on implementation of evidence-based research in clinical settings influenced our assumptions regarding how community-based organizations would use research knowledge. At the outset of this project, if we had more

thoroughly considered the multitude of ways knowledge can be used by community partners, rather than assuming the focus should be changes in practice, we likely could have collaboratively developed a KM strategy that better met the needs of the community-based organization.

Future Directions

Friendship Research

Stakeholders associated with community-based organizations have expressed the need for more effective friendship support strategies for adults with ID. Therefore, we must systematically evaluate strategies to determine their utility and effectiveness in different community-based contexts. In addition to completing community-effectiveness trials to evaluate strategy outcomes, it is imperative to seek out experiential knowledge (of service-users and caregivers) and practice-based knowledge (of service-providers and volunteers) when conducting evaluations. This will contribute to the value of research findings and make them more relevant to stakeholders who ultimately use this information within community-based settings.

In addition to expanding the repertoire of research activities when evaluating friendship strategies, we should consider studying a variety of friendship strategies. Strategies that have been studied previously tend to focus on promoting friendships between individuals with and without ID. Although some individuals with ID have indicated that they have meaningful friendships with individuals who do not have ID (Pottie, 2004; Rossetti, 2011), others have said that they more easily connect with those who have similar levels of functioning and comparable experiences related to having a disability (Cummins & Lau, 2003; Knox & Hickson, 2001; Salmon, 2013). To enhance feelings of belonging and social connectedness, promoting reciprocal

relationships with others who have ID could also be beneficial (Cobigo, Ouellette-Kuntz, Lysaght, & Martin, 2012; Cummins & Lau, 2003; Western, McCrea & Stimson, 2007). In addition to conducting research on strategies that promote friendship between individuals with and without ID, there is a need to evaluate more friendship strategies that facilitate friendships between individuals with ID. Having systematic research findings related to a variety of friendship support strategies can be useful for informing KM in settings who have service-users with varying needs and goals related to friendship.

Knowledge Mobilization Research

The complex and dynamic nature of community-based settings can make KM initiatives challenging. Initial knowledge to action models developed within the health sciences tended to use scientific evidence and tailor it to a given setting. This has led to the development of structured methods for adapting clinical guidelines to different contexts (e.g., Harrison, Legare, Graham, & Fervers, 2010). Unfortunately, thus far it has not been possible to develop such practical tools for community-based settings. For KM initiatives to be successful in community-based settings, we believe that a variety of knowledge types should be integrated from the outset. Incorporating knowledge from a variety of sources is a complex process and there is no clear set of guidelines.

In addition to incorporating multiple types of knowledge, KM activities should be adapted to the local setting to foster sustained changes in practice (Spassiani, Parker Harris, & Hammel, 2016). Given that community-based settings tend to differ widely in their scope of practice, type of services offered, service-providers' expertise, and service-users' needs, the way in which KM activities need to be adapted will likely be unique to each setting. Assessing facilitators and barriers to KM in community-based settings can provide information on how KM

activities can be engaged in to better suit the local setting (Davies et al., 2015; Harrison, Legare, Graham, & Fervers, 2010), ultimately leading to more effective KM.

Worton and colleagues (2017) provide a framework for evaluating community-based KM efforts that focuses on knowledge use goals and the needs of stakeholders to inform KM. A framework such as this promotes evaluation that is not based on assumptions underlying models developed for clinical settings (Worton et al., 2017). Additionally, an interdisciplinary approach to KM research would foster a broader perspective, leading to more thorough evaluation methods. By critically reviewing the assumptions of KM and implementation models in the clinical sector, we can develop more pertinent models of KM in community-based settings.

To better understand how to engage in KM in different settings, we need to systematically and repeatedly evaluate KM processes and identify the activities and adaptations that are effective and ineffective in a variety of contexts (Danseco et al., 2009). Therefore, there is a need to conduct more process evaluations of KM in community-based settings, as findings from a multitude of evaluations will contribute to a more empirically valid list of facilitators and barriers to KM and to strategies for adapting methods to different settings. These findings would in turn contribute to models of community-based KM, which there is a strong need for. KM efforts that are informed by models developed within community-based settings will facilitate more contextually relevant and effective KM.

Conclusion

This dissertation contributes to implementation science by examining KM processes in community-based services for individuals with ID. KM research in community-based services is still in its infancy, so there are relatively few models to inform KM in community-based settings compared to clinical services. Therefore, our methods were informed by implementation

methods informed by the clinical health sector. Our findings highlighted the challenges of engaging in KM activities that rely on assumptions underlying models developed for clinical settings. Based on the facilitators and barriers to KM that we encountered, we discussed practical recommendations for engaging in KM in community-based services. These recommendations can be used to inform KM and implementation research in other community-based settings. Evaluating KM processes in community-based settings will contribute to our understanding of how to effectively tailor activities to be more contextually relevant. In turn, these findings will inform the development of community-based KM models, ultimately leading to more effective outcomes for the populations being served.

References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities, 10*(3), 275–287.
- Abma, T. A., Cook, T., Rämngård, M., Kleba, E., Harris, J., & Wallerstein, N. (2017). Social impact of participatory health research: Collaborative non-linear processes of knowledge mobilization. *Educational Action Research, 25*(4), 489–505.
<https://doi.org/10.1080/09650792.2017.1329092>
- Activating Change Together for Community Food Security: Knowledge Mobilization Working Group, & Group. (2014). *Knowledge mobilization in participatory action research: A synthesis of the literature* (p. 42). Halifax, NS: FoodARC, Mount Saint Vincent University.
- Alvesson, M., & Sveningsson, S. (2008). *Changing organizational culture: Cultural change work in progress*. New York: Routledge.
- American Psychiatric Association. (2000). *Diagnostic and statistical manual-text revision (DSM-IV-TRim, 2000)*. American Psychiatric Association.
- American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders (DSM-5)*. American Psychiatric Pub.
- Arias, B., Ovejero, A., & Morentin, R. (2009). Love and emotional well-being in people with intellectual disabilities. *The Spanish Journal of Psychology, 12*(01), 204-216.
- Articulate. (2019). Rise 360. Retrieved May 7, 2019, from Rise Articulate website:
<https://articulate.com/360/rise>

- Asselt-Goverts, A. E., Embregts, P., Hendriks, A. H. C., & Frielink, N. (2014). Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology*, 24(2), 111–124.
- Balandin, S., Llewellyn, G., Dew, A., & Ballin, L. (2006). ‘We couldn’t function without volunteers’: Volunteering with a disability, the perspective of not-for-profit agencies. *International Journal of Rehabilitation Research*, 29, 131–136.
- Bane, G., Dooher, M., Flaherty, J., Mahon, A., Donagh, P. M., Wolfe, M., . . . Shannon, S. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities*, 40(2), 109-122.
- Barron, K. (2001). Autonomy in everyday life, for whom?. *Disability & Society*, 16(3), 431-447.
- Bauer, M. S., Damschroder, L., Hagedorn, H., Smith, J., & Kilbourne, A. M. (2015). An introduction to implementation science for the non-specialist. *BMC Psychology*, 3(1), 32. <https://doi.org/10.1186/s40359-015-0089-9>
- Bennet, A., Bennet, D. H., Fafard, K., Fonda, M., Lomond, T., Messier, L., & Vaugeois, N. (2007). *Knowledge mobilization in the social sciences and humanities: Moving from research to action*. Frost, WV: MQI Press.
- Bhaumik, S., Tyrer, F., McGrother, C., & Ganghadaran, S. (2008). Psychiatric service use and psychiatric disorders in adults with intellectual disability. *Journal of Intellectual Disability Research*, 52(11), 986-995.

- Bogenschutz, M., Nord, D., & Hewitt, A. (2015). Competency-based training and worker turnover in community supports for people with IDD: Results from a group randomized controlled study. *Intellectual and Developmental Disabilities*, 53(3), 182–195.
<https://doi.org/10.1352/1934-9556-53.3.182>
- Bowen, S., & Graham, I. D. (2013). Integrated knowledge translation. In *Knowledge Translation in Health Care* (pp. 14–23). <https://doi.org/10.1002/9781118413555.ch02>
- Brackenridge, R., & McKenzie, K. (2005). The friendships of people with a learning disability. *Learning Disability Practice*, 8(5), 12-17.
- Braspenning, J., Hermens, R., Calsbeek, H., Westert, G., Campbell, S., & Grol, R. (2013). Quality and safety of care: The role of indicators. In R. Grol, M. Wensing, M. Eccles, & D. Davis (Eds.), *Improving Patient Care: The Implementation of Change in Health Care, Second Edition* (pp. 115–136). United Kingdom: John Wiley & Sons Inc; US.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101.
- Brown, B. B., Feiring, C. and Furman, W. (1999). Missing the love boat: Why researchers have shied away from adolescent romance. In *The Development of Romantic Relationships in Adolescence*, W. Furman et al. (Eds). Cambridge, U.K.: Cambridge University Press.
- Bryen, D. N., Carey, A., & Frantz, B. (2003). Ending the silence: Adults who use augmentative Communication and their Experiences as Victims of Crimes. *Augmentative and Alternative Communication*, 19(2), 125-134.

- Bukowski, W. M., Motzoi, C., & Meyer, F. (2009). Friendship as process, function, and outcome. *Handbook of Peer Interactions, Relationships, and Groups*, 217-231.
- Cameron, E., & Green, M. (2009). *Making sense of change management: A complete guide to the models, tools, & techniques of organizational change*. (2nd ed.). London, UK & Philadelphia, USA: Kogan Page Limited.
- Canadian Observatory on Homelessness. (2018). Community-based mental health care. Retrieved May 2, 2019, from The Homeless Hub Website:
<https://www.homelesshub.ca/about-homelessness/service-provision/community-based-mental-health-care>
- Centers for Disease Control and Prevention. (2014). Types of Evaluation. Retrieved October 26, 2019, from Centers for Disease Control and Prevention website:
<https://www.cdc.gov/std/program/pupesthd.htm>
- Charmaz, K. (2006). Constructing grounded theory: A practical guide through qualitative research. *Sage Publications Ltd, London*.
- Cherrington, A., Ayala, G. X., Elder, J. P., Arredondo, E. M., Fouad, M., & Scarinci, I. (2010). Recognizing the diverse roles of community health workers in the elimination of health disparities: From paid staff to volunteers. *Ethnicity & Disease*, 20(2), 189–194.
- Cobigo, V., Ouellette-Kuntz, H., & Lysaght, R. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2), 75–84.
- Colditz, G. A., & Emmons, K. M. (2017). *The Promise and Challenges of Dissemination and Implementation Research*. Retrieved from

<http://www.oxfordscholarship.com/view/10.1093/oso/9780190683214.001.0001/oso-9780190683214-chapter-1>

- Collins, W. A., & Laursen, B. (2004). Parent-adolescent relationships and influence. In R. Lerner & L. Steinberg (Eds.), *Handbook of adolescent psychology* (pp. 331–362). New York: Wiley.
- Collins, W. A., & Madsen, S. D. (2006). Personal relationships in adolescence and early adulthood. In A. L. Vangelisti & D. Perlman (Eds.), *The Cambridge handbook of personal relationships* (pp. 191–209). New York: Cambridge University Press.
- Connolly, J. and Goldberg, A. (1999). Romantic relationships in adolescence. The role of friends and peers in their emergence and development. In *The Development of Romantic Relationships in Adolescence*, W. Furman et al. (Eds). Cambridge, U.K.: Cambridge University Press.
- Contandriopoulos, D., Lemire, M., Denis, J.-L., & Tremblay, E. (2010). Knowledge exchange processes in organizations and policy arenas: A narrative systematic review of the literature. *The Milbank Quarterly*, 88(4), 444–483. <https://doi.org/10.1111/j.1468-0009.2010.00608.x>
- Cooper, A. (2014). Knowledge mobilisation in education across Canada: A cross-case analysis of 44 research brokering organisations. *Evidence & Policy: A Journal of Research, Debate and Practice*, 10(1), 29–59. <https://doi.org/10.1332/174426413X662806>
- Corrigan, P. W., Bink, A. B., Fokuo, J. K., & Schmidt, A. (2015). The public stigma of mental illness means a difference between you and me. *Psychiatry Research*, 226(1), 186–191. <https://doi.org/10.1016/j.psychres.2014.12.047>

- Creswell, J. W., & Miller, D. L. (2000). Determining validity in qualitative inquiry. *Theory into Practice*, 39(3), 124-130.
- Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(2), 145-157.
- Cuskelly, M., & Bryde, R. (2004). Attitudes towards the sexuality of adults with an intellectual disability: Parents, support staff, and a community sample. *Journal of Intellectual and Developmental Disability*, 29(3), 255-264.
- Damschroder, L. J., Aron, D. C., Keith, R. E., Kirsh, S. R., Alexander, J. A., & Lowery, J. C. (2009). Fostering implementation of health services research findings into practice: A consolidated framework for advancing implementation science. *Implementation Science*, 4(1). <https://doi.org/10.1186/1748-5908-4-50>
- Dansecu, E., Sundar, P., Kasprzak, S., Witteveen, T., Woltman, H., & Manion, I. (2009). Are we there yet? Evaluation and the knowledge translation journey. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(1), 7–15.
- Davies, H. T., Nutley, S. M., & Mannion, R. (2000). Organisational culture and quality of health care. *BMJ Quality & Safety*, 9(2), 111–119.
- Dearing, J. W., Kee, K. F., & Peng, T.-Q. (2017). *Historical Roots of Dissemination and Implementation Science*. Retrieved from <http://www.oxfordscholarship.com/view/10.1093/oso/9780190683214.001.0001/oso-9780190683214-chapter-3>

- Department of Health (2007) *Valuing people now: From progress to transformation – a consultation on the next three years of learning disability policy*. London, Department of Health.
- Dion, K. K., & Dion, K. L. (1996). Cultural perspectives on romantic love. *Personal Relationships*, 3(1), 5-17.
- Dolcini, M. M., Gandelman, A., Vogan, S. A., Kong, C., Leak, T.-N., King, A. J., ... O'Leary, A. (2010). Translating HIV interventions into practice: Community-based organizations' experiences with the diffusion of effective behavioral interventions (DEBIs). *Social Science & Medicine* (1982), 71(10), 1839–1846.
<https://doi.org/10.1016/j.socscimed.2010.08.011>
- Dückers, M. L. A., Spreeuwenberg, P., Wagner, C., & Groenewegen, P. P. (2009). Exploring the black box of quality improvement collaboratives: Modelling relations between conditions, applied changes and outcomes. *Implementation Science: IS*, 4, 74.
<https://doi.org/10.1186/1748-5908-4-74>
- Dukes, E., & McGuire, B. E. (2009). Enhancing capacity to make sexuality-related decisions in people with an intellectual disability. *Journal of Intellectual Disability Research*, 53(8), 727-734.
- Eastgate, G., Van Driel, M. L., Lennox, N., & Scheermeyer, E. (2011). Women with intellectual disabilities: A study of sexuality, sexual abuse and protection skills. *Australian Family Physician*, 40(4), 226.

Emerson, E., & McVilly, K. (2004). Friendship activities of adults with intellectual disabilities in supported accommodation in northern England. *Journal of Applied Research in Intellectual Disabilities*, 17(3), 191-197.

Employment and Social Development Canada. (2017, November 30). The Government of Canada tables the Optional Protocol to the United Nations Convention on the Rights of Persons with Disabilities [News releases]. Retrieved May 3, 2019, from Government of Canada website: https://www.canada.ca/en/employment-social-development/news/2017/11/the_government_ofcanadatablestheoptionalprotocoltotheunit ednatio.html

Estabrooks, C. A., Thompson, D. S., Lovely, J. J. E., & Hofmeyer, A. (2006). A guide to knowledge translation theory. *Journal of Continuing Education in the Health Professions*, 26(1), 25–36. <https://doi.org/10.1002/chp.48>

Evans, D. S., McGuire, B. E., Healy, E., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part II: Staff and family carer perspectives. *Journal of Intellectual Disability Research*, 53(11), 913-921.

Financial Consumer Agency of Canada. (2018). CG-3 Clear language and presentation principles and guidelines for the industry [Guidance - legislative]. Retrieved May 3, 2019, from Government of Canada website: <https://www.canada.ca/en/financial-consumer-agency/services/industry/commissioner-guidance/guidance-3.html>

Finlay, W. M. L., Walton, C., & Antaki, C. (2008). Promoting choice and control in residential services for people with learning disabilities. *Disability & Society*, 23(4), 349–360. <https://doi.org/10.1080/09687590802038860>

- Fiori, K. L., Antonucci, T. C., & Cortina, K. S. (2006). Social network typologies and mental health among older adults. *The Journals of Gerontology. Series B, Psychological Sciences and Social Sciences*, 61(1), P25-32.
- Fistein, E., Holland, A., Clare, I., & Gunn, M. (2009) A comparison of mental health legislation from diverse commonwealth jurisdictions. *International Journal of Law and Psychiatry*, 32, 147–155.
- Fitzgerald, C., & Withers, P. (2013). ‘I don’t know what a proper woman means’: What women with intellectual disabilities think about sex, sexuality and themselves. *British Journal of Learning Disabilities*, 41(1), 5-12.
- Fraley, R., & Davis, K. E. (1997). Attachment formation and transfer in young adults’ close friendships and romantic relationships. *Personal Relationships*, 4, 131–144.
- Friedman, C., & Rizzolo, M. C. (2018). Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 30(1), 39–54. <https://doi.org/10.1007/s10882-017-9576-7>
- Fulford, C., & Cobigo, V. (2016). Friendships and Intimate Relationships among People with Intellectual Disabilities: A Thematic Synthesis. *Journal of Applied Research in Intellectual Disabilities*, n/a-n/a. <https://doi.org/10.1111/jar.12312>
- Fulford, C., & Cobigo, V. (2018a). *A discussion about friendship support for adults with intellectual disabilities*. Online Presentation presented at the La Ressource, Ottawa, Ontario. La Ressource, Ottawa, Ontario.
- Fulford, C., & Cobigo, V. (2018b). Adapter et mettre en œuvre des mesures de soutien aux amitiés pour les adultes ayant une déficience intellectuelle - Overview | Rise 360 [Online

Modules]. Retrieved May 7, 2019, from Rise Articulate website:

<https://rise.articulate.com/share/yEPXMPg-50YbexZsHfPtQaclGE8qDATZ#/>

Fulford, C., & Cobigo, V. (2018c). Adapting and implementing friendship supports for adults with intellectual disabilities. [Educational Modules]. Retrieved May 7, 2019, from Rise Articulate website:

https://rise.articulate.com/share/9OZ3LjwsDcdW6nJA16SQZb1Tk_M6QNAO#/?_k=w6h1uy

Fulford, C., & Cobigo, V. (2018d). *How to implement evidence-based friendship support strategies for adults with developmental disabilities who have complex needs*. Presented at the Ontario Association on Developmental Disabilities Conference, Kingston, ON.

Fulford, C., & Cobigo, V. (2018e). *Une discussion au sujet du soutien à l'amitié pour les adultes ayant une déficience intellectuelle*. Online Presentation presented at the La Ressource, Ottawa, Ontario. La Ressource, Ottawa, Ontario.

Fulford, C., Cobigo, V., & Ressel, M. (2017). *Exploring strategies to support friendships for adults with intellectual disabilities: An Evidence Brief* (No. 1; p. 32). Ottawa, ON: University of Ottawa.

Fulford, C., Cobigo, V., & Ressel, M. (2018). *Adapting Friendship Support Strategies to meet the needs of Adults with Intellectual Disabilities and their Caregivers* (p. 19). Ottawa, ON: University of Ottawa.

Fulford, C., Ressel, M., & Cobigo, V. (Unpublished manuscript). *A Review of Strategies to Support Friendships for Adults with Intellectual and Developmental Disabilities*. Ottawa, ON.

- Gagliardi, A. R., Berta, W., Kothari, A., Boyko, J., & Urquhart, R. (2016). Integrated knowledge translation (IKT) in health care: a scoping review. *Implementation Science*, 11(1), 38. <https://doi.org/10.1186/s13012-016-0399-1>
- Gaglio, B., & Glasgow, R. E. (2017). *Evaluation Approaches for Dissemination and Implementation Research*. Retrieved from <http://www.oxfordscholarship.com/view/10.1093/oso/9780190683214.001.0001/oso-9780190683214-chapter-19>
- Gainforth, H. L., Latimer-Cheung, A. E., Athanasopoulos, P., Moore, S., & Ginis, K. A. (2014). The role of interpersonal communication in the process of knowledge mobilization within a community-based organization: a network analysis. *Implementation Science*, 9(1), 59.
- Gainforth, H. L., Latimer-Cheung, A. E., Moore, S., Athanasopoulos, P., & Martin Ginis, K. A. (2015). Using network analysis to understand knowledge mobilization in a community-based organization. *International Journal of Behavioral Medicine*, 22(3), 292–300. <https://doi.org/10.1007/s12529-014-9430-6>
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Glidden, L. M., Bamberger, K. T., Draheim, A. R., & Kersh, J. (2011). Parent and athlete perceptions of Special Olympics participation: Utility and danger of proxy responding. *Intellectual and Developmental Disabilities*, 49(1), 37-45.

Goldner, E. M., Jeffries, V., Bilsker, D., Jenkins, E., Menear, M., & Petermann, L. (2011).

Knowledge Translation in Mental Health: A Scoping Review. *Healthcare Policy*, 7(2), 83–98.

Google. (2017). How Google Search Works. Retrieved August 30, 2017, from Search Console

Help website: <https://support.google.com/webmasters/answer/70897?hl=en>

Government of California. (2019). Community Based Organizations (CBOs). Retrieved May

2, 2019, from California Department of Healthcare Services website:

[https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/Community-Based-Organizations-\(CBOs\).aspx](https://www.dhcs.ca.gov/services/medi-cal/eligibility/Pages/Community-Based-Organizations-(CBOs).aspx)

Government of Canada, C. I. of H. R. (2010, September 8). Section 5.1 Knowledge

dissemination and exchange of knowledge - Knowledge Translation in Health Care -

CIHR. Retrieved April 30, 2019, from <http://www.cihr-irsc.gc.ca/e/41953.html>

Government of Canada, C. I. of H. R. (2010a, September 8). Section 1.1 Knowledge to action:

what it is and what it isn't - Knowledge Translation in Health Care - CIHR. Retrieved

April 30, 2019, from <http://www.cihr-irsc.gc.ca/e/41928.html>

Government of Canada, C. I. of H. R. (2010b, September 8). Section 3.1: The Action Cycle -

Knowledge Translation in Health Care - CIHR. Retrieved April 30, 2019, from

<http://www.cihr-irsc.gc.ca/e/41929.html>

Government of Canada, C. I. of H. R. (2012, May 25). A Guide to Researcher and Knowledge-

User Collaboration in Health Research - CIHR. Retrieved April 30, 2019, from

<http://www.cihr-irsc.gc.ca/e/44954.html>

Government of Canada, C. I. of H. R. (2016). About us - CIHR. Retrieved April 30, 2019, from <http://www.cihr-irsc.gc.ca/e/29418.html#2>

Government of Canada, S. (2012, May 11). Guidelines for Effective Knowledge Mobilization. Retrieved February 4, 2016, from http://www.sshrc-crsh.gc.ca/funding-financement/policies-politiques/knowledge_mobilisation-mobilisation_des_connaissances-eng.aspx

Government of Canada. (2015). Guide to Knowledge Translation Planning at CIHR: Integrated and End-of-Grant Approaches. Retrieved February 4, 2016, from Canadian Institutes of Health Research website: <http://www.cihr-irsc.gc.ca/e/45321.html>

Government of Canada. (2018). Definition of Terms. Retrieved May 3, 2019, from Social Sciences and Humanities Research Council website: <http://www.sshrc-crsh.gc.ca/funding-financement/programs-programmes/definitions-eng.aspx#km-mc>

Government of Ontario, Ministry of Community and Social Services. (2013). Legislation. Retrieved February 4, 2016, from <http://www.mcass.gov.on.ca/en/mcass/programs/developmental/improving/legislation.aspx>

Government of Ontario, Ministry of Community and Social Services. (2015). Developmental services in Ontario. Retrieved February 4, 2016, from <http://www.mcass.gov.on.ca/en/mcass/programs/developmental/index.aspx>

Government of Ontario. (2018). Help with daily living. Retrieved May 1, 2019, from Ministry of Community and Social Services website: <https://www.mcass.gov.on.ca/en/mcass/programs/developmental/serviceSupport/passport.aspx>

Government of Ontario. (2019). Community Health Centres. Retrieved May 24, 2019, from Ministry of Health and Long-Term Care website:

<http://www.health.gov.on.ca/en/common/system/services/chc/>

Government of Ontario. *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, c. 14.* , (2008).

Graham, I. D., Tetroe, J., & KT Theories Research Group. (2007). Some Theoretical Underpinnings of Knowledge Translation. *Academic Emergency Medicine*, 14(11), 936–941. <https://doi.org/10.1197/j.aem.2007.07.004>

Graham, Ian D., & Tetroe, J. (2009). Planned action theories. *Knowledge Translation in Health Care: Moving from Evidence to Practice*, 185, 195.

Graham, Ian D., & Tetroe, J. M. (2009). Getting evidence into policy and practice: perspective of a health research funder. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 18(1), 47.

Graham, Ian D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006). Lost in knowledge translation: Time for a map? *Journal of Continuing Education in the Health Professions*, 26(1), 13–24. <https://doi.org/10.1002/chp.47>

Greenhalgh, T., Jackson, C., Shaw, S., & Janamian, T. (2016). Achieving research impact through co-creation in community-based health services: literature review and case study. *The Milbank Quarterly*, 94(2), 392–429.

Grimshaw, J. M., Eccles, M. P., Lavis, J. N., Hill, S. J., & Squires, J. E. (2012). Knowledge translation of research findings. *Implementation Science*, 7(1), 50.

- Grol, R., & Wensing, M. (2013). Characteristics of successful innovations. In *Improving Patient Care* (pp. 77–90). <https://doi.org/10.1002/9781118525975.ch5>
- Grol, R., & Wensing, M. (2013). Dissemination of innovations. In *Improving Patient Care* (pp. 185–196). <https://doi.org/10.1002/9781118525975.ch11>
- Grol, R., & Wensing, M. (2013). Effective implementation of change in healthcare: A systematic approach. *Improving Patient Care: The Implementation of Change in Health Care, Second Edition*, 40–63.
- Grol, R., Bosch, M., & Wensing, M. (2013). Development and selection of strategies for improving patient care. In R. Grol, M. Wensing, M. Eccles, & D. Davis (Eds.), *Improving Patient Care: The Implementation of Change in Health Care, Second Edition* (pp. 165–184). United Kingdom: John Wiley & Sons.
- Grol, R., Ouwens, M., & Wollersheim, H. (2013). Planning and organizing the change process. In R. Grol, M. Wensing, M. Eccles, & D. Davis (Eds.), *Improving Patient Care: The Implementation of Change in Health Care, Second Edition* (pp. 64–76). Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/9781118525975.ch4/summary>
- Grol, R., Wensing, M., Bosch, M., Hulscher, M., & Eccles, M. (2013). Theories on implementation of change in healthcare. In R. Grol, M. Wensing, M. Eccles, & D. Davis (Eds.), *Improving Patient Care* (pp. 18–39). Retrieved from <http://onlinelibrary.wiley.com/doi/10.1002/9781118525975.ch2/summary>
- Grol, R., Wensing, M., Eccles, M., & Davis, D. (2013). *Improving patient care: the implementation of change in health care*. John Wiley & Sons.

Hardman, M. L., & Clark, C. (2006). Promoting friendship through best buddies: A national survey of college program participants. *Mental Retardation*, 44(1), 56–63.

<https://doi.org/2>

Hardwick, R., Anderson, R., & Cooper, C. (2015). How do third sector organisations use research and other knowledge? A systematic scoping review. *Implementation Science: IS*, 10, 84. <https://doi.org/10.1186/s13012-015-0265-6>

<https://doi.org/10.1186/s13012-015-0265-6>

Harrison, M. B., Legare, F., Graham, I. D., & Fervers, B. (2010). Adapting clinical practice guidelines to local context and assessing barriers to their use. *Canadian Medical Association Journal*, 182(2), E78–E84. <https://doi.org/10.1503/cmaj.081232>

<https://doi.org/10.1503/cmaj.081232>

Havercamp, S. M., Scandlin, D., & Roth, M. (2004). Health disparities among adults with developmental disabilities, adults with other disabilities, and adults not reporting disability in North Carolina. *Public Health Reports*, 119(4), 418–426.

Healy, E., McGuire, B., Evans, D., & Carley, S. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*, 53(11), 905–912.

Hefner, J., & Eisenberg, D. (2009). Social support and mental health among college students. *American Journal of Orthopsychiatry*, 79(4), 491.

Hering, J. G. (2016). Do we need “more research” or better implementation through knowledge brokering? *Sustainability Science*, 11(2), 363–369.

<https://doi.org/10.1007/s11625-015-0314-8>

- Hollomotz, A. (2009). ‘May we please have sex tonight?’ – People with learning difficulties pursuing privacy in residential group settings. *British Journal of Learning Disabilities*, 37(2), 91-97.
- Howarth, S., Morris, D., Newlin, M., & Webber, M. (2016). Health and social care interventions which promote social participation for adults with learning disabilities: A review. *British Journal of Learning Disabilities*, 44(1), 3–15.
- Hughes, A., & Walden, S. (1999). Befriending: A note of caution. *British Journal of Learning Disabilities*, 27(3), 88–92.
- Hulscher, M., Laurant, M., & Grol, R. (2013). Process evaluation of implementation strategies. In R. Grol, M. Wensing, rtin Eccles, & D. Davis (Eds.), *Improving Patient Care: The Implementation of Change in Health Care, Second Edition* (pp. 333–349). United Kingdom: John Wiley & Sons.
- Hurd, C., Evans, C., & Renwick, R. (2018). “Having friends is like having marshmallows”: Perspectives of transition-aged youths with intellectual and developmental disabilities on friendship. *Journal of Applied Research in Intellectual Disabilities*, 31(6), 1186–1196. <https://doi.org/10.1111/jar.12493>
- Hwang, E. H., Singh, P. V., & Argote, L. (2015). Knowledge sharing in online communities: learning to cross geographic and hierarchical boundaries. *Organization Science*, 26(6), 1593–1611. <https://doi.org/10.1287/orsc.2015.1009>
- Inclusive Research Network. (2010). *Relationships and supports study: People with intellectual disabilities in Ireland*. Dublin: National Institute for Intellectual Disability Ireland; Galway: National Federation of Voluntary Bodies.

- Inclusive Research Network. (2010). *Relationships and supports study: People with intellectual disabilities in Ireland*. Retrieved from Dublin: National Institute for Intellectual Disability Ireland; Galway: National Federation of Voluntary Bodies.
- Website:
http://www.fedvol.ie/_fileupload/Relationships%20and%20Supports%20Report%202010.pdf
- Jahoda, A., Wilson, A., Stalker, K., & Cairney, A. (2010). Living with stigma and the self-perceptions of people with mild intellectual disabilities. *Journal of Social Issues*, 66(3), 521–534. <https://doi.org/10.1111/j.1540-4560.2010.01660.x>
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban Health*, 78(3), 458-467.
- Kelly, G., Crowley, H., & Hamilton, C. (2009). Rights, sexuality and relationships in Ireland: ‘It’d be nice to be kind of trusted’. *British Journal of Learning Disabilities*, 37(4), 308-315.
- Kersh, J., Corona, L., & Siperstein, G. (2013). Social well-being and friendship of people with intellectual disability. *The Oxford handbook of positive psychology and disability*, 60-81.
- Kersten, M. C. O., Taminiau, E. F., Schuurman, M. I. M., Weggeman, M. C. D. P., & Embregts, P. J. C. M. (2018). How to improve sharing and application of knowledge in care and support for people with intellectual disabilities? A systematic review: Improving sharing and application of knowledge. *Journal of Intellectual Disability Research*, 62(6), 496–520. <https://doi.org/10.1111/jir.12491>

Kislov, R., Wilson, P., & Boaden, R. (2017). The 'dark side' of knowledge brokering. *Journal of Health Services Research & Policy*, 22(2), 107–112.

<https://doi.org/10.1177/1355819616653981>

Knight, K. (2013). The changing face of the 'good mother': Trends in research into families with a child with intellectual disability, and some concerns. *Disability & Society*, 28(5), 660-673.

Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 276-291.

Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 276–291.

Kothari, A., & Armstrong, R. (2011). Community-based knowledge translation: Unexplored opportunities. *Implement Sci*, 6(1), 59.

Kothari, A., & Wathen, C. N. (2013). A critical second look at integrated knowledge translation. *Health Policy*, 109(2), 187–191.

<https://doi.org/10.1016/j.healthpol.2012.11.004>

Kothari, A., McCutcheon, C., & Graham, I. D. (2017). Defining integrated knowledge translation and moving forward: A response to recent commentaries. *International Journal of Health Policy and Management*, 6(5), 299–300.

<https://doi.org/10.15171/ijhpm.2017.15>

- Lafferty, A., McConkey, R., & Taggart, L. (2013). Beyond friendship: The nature and meaning of close personal relationships as perceived by people with learning disabilities. *Disability & Society*, 28(8), 1074-1088.
- Lapaige, V. (2010). “Integrated knowledge translation” for globally oriented public health practitioners and scientists: Framing together a sustainable transfrontier knowledge translation vision. *Journal of Multidisciplinary Healthcare*, 3, 33–47.
- Learning Disability Service at Leeds and York Partnership NHS Foundation Trust. (2019). What is easy read? Retrieved May 3, 2019, from Accessible Information Standard website: <http://www.easyonthei.nhs.uk/accessible-information-standard-what-is-easy-read>
- Lemay, R. A. (2009). Deinstitutionalization of people with developmental disabilities: A review of the literature. *Canadian Journal of Community Mental Health*, 28(1), 181–194.
- Levac, D., Glegg, S. M. N., Camden, C., Rivard, L. M., & Missiuna, C. (2015). Best practice recommendations for the development, implementation, and evaluation of online knowledge translation resources in rehabilitation. *Physical Therapy*, 95(4), 648–662. <https://doi.org/10.2522/ptj.20130500>
- Levin, B. (2008). Thinking about knowledge mobilization. *An Invitational Symposium Sponsored by the Canadian Council on Learning and the Social Sciences and Humanities Research Council of Canada*, 15–18. Retrieved from http://en.copian.ca/library/research/ccl/knowledge_mobilization/knowledge_mobilization.pdf

- Lin, E., Balogh, R., Isaacs, B., Ouellette-Kuntz, H., Selick, A., Wilton, A. S., ... Lunskey, Y. (2014). Strengths and Limitations of Health and Disability Support Administrative Databases for Population-Based Health Research in Intellectual and Developmental Disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 11(4), 235–244.
- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53, 463–473.
<https://doi.org/10.1111/j.1365-2788.2009.01170.x>
- Löfgren-Mårtenson, L. (2004). “May I?” About sexuality and love in the new generation with intellectual disabilities. *Sexuality and Disability*, 22(3), 197-207.
- Lunskey, Y., & Benson, B. (2001). Association between perceived social support and strain, and positive and negative outcome for adults with mild intellectual disability. *Journal of Intellectual Disability Research*, 45(2), 106–114.
- Mactavish, J. B., Mahon, M. J., & Lutfiyya, Z. M. (2000). “I can speak for myself”: Involving individuals with intellectual disabilities as research participants. *Mental Retardation*, 38(3), 216-227.
- Mahar, A. L., Cobigo, V., & Stuart, H. (2013). Conceptualizing belonging. *Disability and rehabilitation*, 35(12), 1026-1032.
- Manojlovich, M., Squires, J. E., Davies, B., & Graham, I. D. (2015). Hiding in plain sight: communication theory in implementation science. *Implementation Science*, 10(1), 58.
<https://doi.org/10.1186/s13012-015-0244-y>
- Marmot, M., & Wilkinson, R. (2005). *Social determinants of health*. Oxford University Press.

- Martin, T., Shooshtari, S., Temple, B., & Yu, C. T. (2010). Facilitating and impeding factors for knowledge translation in developmental disabilities: Outcomes of community-based workshops. *Journal on Developmental Disabilities, 16*(3), 41–47.
- Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities, 26*(2), 108–118. <https://doi.org/10.1111/jar.12001>;
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research, 54*(8), 691–700.
- McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through unified sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disability Research, 57*(10), 923–935.
- McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw, K., & Hindmarsh, G. (2009). Strengthening the social relationships of mothers with learning difficulties. *British Journal of Learning Disabilities, 37*(1), 66–75.
- McGrath, P. J., Lingley-Pottie, P., Emberly, D. J., Thurston, C., & McLean, C. (2009). Integrated Knowledge Translation in Mental Health: Family Help as an Example. *Journal of the Canadian Academy of Child and Adolescent Psychiatry, 18*(1), 30–37.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. (2006). ‘I get by with a little help from my friends’: Adults with intellectual disability discuss loneliness. *Journal of Applied Research in Intellectual Disabilities, 19*(2), 191–203. <https://doi.org/10.1111/j.1468-3148.2005.00261.x>

- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). Self-advocates have the last say on friendship. *Disability, Handicap & Society*, 21(7), 693–708. <https://doi.org/10.1080/09687590600995287>
- Medvene, L. J., Nilsen, K. M., Smith, R., Ofei-Dodoo, S., DiLollo, A., Webster, N., ... & Nance, A. (2016). Social networks and links to isolation and loneliness among elderly HCBS clients. *Aging & mental health*, 20(5), 485-493.
- Meyers, A. B., Meyers, J., Graybill, E. C., Proctor, S. L., & Huddleston, L. (2012). Ecological approaches to organizational consultation and systems change in educational settings. *Journal of Educational and Psychological Consultation*, 22(1–2), 106–124. <https://doi.org/10.1080/10474412.2011.649649>
- Miles, M. B., Huberman, A. M., & Saldana, J. (2013). *Qualitative data analysis: A methods sourcebook*. Retrieved from <https://books-google-ca.proxy.bib.uottawa.ca/books?hl=en&lr=&id=3CNrUbTu6CsC&oi=fnd&pg=PR1&dq=miles,+huberman,+and+saldana&ots=Lg81ojZN7b&sig=TGIIJ0sHnSKVl91qKvOkQWFaYjU>
- Miller, B. C., & Benson, B. (1999). Romantic and sexual relationship development during adolescence. *The development of romantic relationships in adolescence*, 99-121.
- Mitton, C., Adair, C. E., McKenzie, E., Patten, S. B., & Perry, B. W. (2007). Knowledge transfer and exchange: rReview and synthesis of the literature. *Milbank Quarterly*, 85(4), 729–768.
- Montesanti, S. R., Abelson, J., Lavis, J. N., & Dunn, J. R. (2015). The value of frameworks as knowledge translation mechanisms to guide community participation practice in Ontario

CHCs. *Social Science & Medicine* (1982), 142, 223–231.

<https://doi.org/10.1016/j.socscimed.2015.08.024>

Multidimensional Assessment of Providers and Systems. (2016). Who We Are. Retrieved May

7, 2019, from MAPS Research website: <https://www.mapsresearch.ca/who-we-are/>

Naidorf, J. C. (2014). Knowledge utility: From social relevance to knowledge mobilization.

Education Policy Analysis Archives, 22(0), 89.

<https://doi.org/10.14507/epaa.v22n89.2014>

National Institute for Intellectual Disability. (2009). *All we want to say: Life in Ireland for*

people with intellectual disabilities. Dublin: Trinity College.

Nilsen, P. (2015). Making sense of implementation theories, models and frameworks.

Implementation Science, 10(1). <https://doi.org/10.1186/s13012-015-0242-0>

Nosek, M. A., Howland, C. A. & Young, M. E. (1997). Abuse of women with disabilities:

Policy implications. *Journal of Disability Policy Studies*, 8, 157 – 175.

Ogden, T., & Fixsen, D. L. (2014). Implementation science: A brief overview and a look

ahead. *Zeitschrift Für Psychologie*, 222(1), 4–11. [https://doi.org/10.1027/2151-](https://doi.org/10.1027/2151-2604/a000160)

[2604/a000160](https://doi.org/10.1027/2151-2604/a000160)

Owczarzak, J. (2012). Evidence-based HIV prevention in community settings: Provider

perspectives on evidence and effectiveness. *Critical Public Health*, 22(1), 73–84.

<https://doi.org/10.1080/09581596.2011.566918>

Parlalis, S. (2011). Organizational changes and job satisfaction among support staff. *Journal of*

Social Service Research, 37(2), 197–216.

<https://doi.org/10.1080/01488376.2011.547737>

PBWORKS. (2019). Nonprofit Organizations / CBOs - Introduction. Retrieved May 2, 2019, from [http://eder671nonprofit.pbworks.com/w/page/18541471/CBOs%20-](http://eder671nonprofit.pbworks.com/w/page/18541471/CBOs%20-%20Introduction)

[%20Introduction](http://eder671nonprofit.pbworks.com/w/page/18541471/CBOs%20-%20Introduction)

Pestka, K., & Wendt, S. (2014). Belonging: Women living with intellectual disabilities and experiences of domestic violence. *Disability & Society*, 29(7), 1031-1045.

Pluye, P., Robert, E., Cargo, M., Bartlett, G., O’Cathain, A., Griffiths, F., ... Rousseau, M. C. (2011). Proposal: A mixed methods appraisal tool for systematic mixed studies reviews. *Montréal: McGill University*, 1–8.

Pottie, C. & S., J. (2004). Friendships between persons with and without developmental disabilities. *Mental Retardation*, 42(1), 55-66.

Rabin, B. A., & Brownson, R. C. (2017). *Terminology for Dissemination and Implementation Research*. Retrieved from <http://www.oxfordscholarship.com/view/10.1093/oso/9780190683214.001.0001/oso-9780190683214-chapter-2>

Ramanadhan, S., & Viswanath, K. (2013). Priority setting for evidence-based health outreach in community-based organizations: A mixed-methods study in three Massachusetts communities. *Translational Behavioral Medicine*, 3(2), 180–188.
<https://doi.org/10.1007/s13142-012-0191-y>

Reeder, H. M. (2000). 'I like you... as a friend': The role of attraction in cross-sex friendship. *Journal of Social and Personal Relationships*, 17(3), 329-348.

- Riger, S., & Sigurvinsdottir, R. (2015). Thematic analysis. *Handbook of Methodological Approaches to Community Based Research: Qualitative, Quantitative and Mixed Methods*, 33–41.
- Roberts, A., Townsend, S., Morris, J., Rushbrooke, E., Greenhill, B., Whitehead, R., ... Golding, L. (2013). Treat me right, treat me equal: Using national policy and legislation to create positive changes in local health services for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 26(1), 14–25.
<https://doi.org/10.1111/jar.12009>
- Rossetti, Z. S. (2011). "That's how we do it": Friendship work between high school students with and without autism or developmental disability. *Research & Practice for Persons with Severe Disabilities*, 36(1), 23-33.
- Rossi, P. H., Lipsey, M. W., & Freeman, H. E. (2003). *Evaluation: A Systematic Approach*. SAGE Publications.
- Runnion, V. M., & Wolfer, T. A. (2004). Relationship disruption in adults with cognitive disabilities. *Families in Society: The Journal of Contemporary Social Services*, 85(2), 205-213.
- Rushbrooke, E., Murray, C., & Townsend, S. (2014). The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities : JARID*, 27(6), 531–541. <https://doi.org/10.1111/jar.12091>;
- Saaltink, R., MacKinnon, G., Owen, F., & Tardif-Williams, C. (2012). Protection, participation and protection through participation: Young people with intellectual

disabilities and decision making in the famil context. *Journal of Intellectual Disability Research*, 56(11), 1076-1086.

Salmon, N. (2013). 'We just stick together': How disabled teens negotiate stigma to create lasting friendship. *Journal of Intellectual Disability Research*, 57(4), 347-358.

Schalock, R. L., & Verdugo, M.-A. (2013). The transformation of disabilities organizations. *Intellectual and Developmental Disabilities*, 51(4), 273–286.
<https://doi.org/10.1352/1934-9556-51.4.273>

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H., Coulter, D. L., Craig, E. M., ... & Shogren, K. A. (2010). Intellectual disability: Definition, classification, and systems of supports. Washington, DC: American Association on Intellectual and Developmental Disabilities.

Schalock, R. L., Verdugo, M. A., & Gomez, L. E. (2011). Evidence-based practices in the field of intellectual and developmental disabilities: An international consensus approach. *Evaluation and Program Planning*, 34(3), 273–282.
<https://doi.org/10.1016/j.evalprogplan.2010.10.004>

Schryer-Roy, A.-M. (2005). Knowledge translation: Basic theories, approaches and applications.

Scott, H. M., & Haverkamp, S. M. (2018). Promoting wellness in people with intellectual and developmental disabilities through relationships. *Current Developmental Disorders Reports*, 5(3), 150–156. <https://doi.org/10.1007/s40474-018-0144-3>

Scottish Executive. (2000). The Same as You? A Review of Services for People with Learning Disabilities. Edinburgh, Scotland: Her Majesty's Stationary Office.

Services and Supports to promote the Inclusion of Persons with Developmental Disabilities

Act (2008, c. 14). Retrieved from the Government of Ontario website:

<http://www.ontario.ca/laws/statute/08s14>

Sheridan, A. J., Drennan, J., Coughlan, B., O’Keeffe, D., Frazer, K., Kemple, M., ... &

O’Callaghan, E. (2015). Improving social functioning and reducing social isolation and loneliness among people with enduring mental illness: Report of a randomised controlled trial of supported socialisation. *International Journal of Social Psychiatry*, 61(3), 241-250.

Sherman, A. M., De Vries, B., & Lansford, J. E. (2000). Friendship in childhood and adulthood: Lessons across the life span. *The International Journal of Aging and Human Development*, 51(1), 31-51.

Shooshtari, S. (2012). Factors that facilitate and impede effective knowledge translation in population health promotion: Results from a consultation workshop in Iran. *Health Promotion Perspectives*, 2(2), 126.

Shooshtari, S., Samadi, S. A., Zarei, K., Naghipur, S., Martin, T., & Lee, M. (2014).

Facilitating and impeding factors for knowledge translation in intellectual and developmental disabilities: Results from a consultation workshop in Iran. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 210–216.

<https://doi.org/10.1111/jppi.12084>

Simpson A, Lafferty A, & McConkey R. (2006). *Out of the shadows: A report of the sexual health and wellbeing of people with learning disabilities in Northern Ireland*. Belfast: FPA.

- Singh, J. (2013). Critical appraisal skills programme. *Journal of Pharmacology and Pharmacotherapeutics*, 4(1), 76.
- Spassiani, N. A., Parker Harris, S., & Hammel, J. (2016). Exploring how knowledge translation can improve sustainability of community-based health initiatives for people with intellectual/developmental disabilities. *Journal of Applied Research in Intellectual Disabilities*, 29(5), 433–444. <https://doi.org/10.1111/jar.12202>
- Sprecher, S. (2013). *Handbook of relationship initiation*. Routledge.
- Stack, E., & McDonald, K. E. (2014). Nothing About Us Without Us: Does Action Research in Developmental Disabilities Research Measure Up? *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 83–91.
- Straus, S. E., Tetroe, J. M., & Graham, I. D. (2011). Knowledge translation is the use of knowledge in health care decision making. *Journal of Clinical Epidemiology*, 64(1), 6–10. <https://doi.org/10.1016/j.jclinepi.2009.08.016>
- Straus, S. E., Tetroe, J., & Graham, I. (2009). Defining knowledge translation. *Canadian Medical Association Journal*, 181(3–4), 165–168. <https://doi.org/10.1503/cmaj.081229>
- Straus, Sharon E., & Leung, E. (2010). *The K in KT: Knowledge Creation*. Retrieved from http://www.cihr-irsc.gc.ca/e/documents/kt_in_health_care_chapter_2.1_e.pdf
- Straus, Sharon E., Tetroe, J. M., & Graham, I. D. (2011). Knowledge translation is the use of knowledge in health care decision making. *Journal of Clinical Epidemiology*, 64(1), 6–10. <https://doi.org/10.1016/j.jclinepi.2009.08.016>

Straus, Sharon E., Tetroe, J., & Graham, I. D. (2013). Introduction Knowledge translation:

What it is and what it isn't. In *Knowledge Translation in Health Care* (pp. 1–13).

<https://doi.org/10.1002/9781118413555.ch01>

Sullivan, F., Bowden, K., McKenzie, K., & Quayle, E. (2013). 'Touching people in

relationships': A qualitative study of close relationships for people with an intellectual disability. *Journal of Clinical Nursing*, 22(23-24), 3456-3466.

Tabak, R. G., Chambers, D. A., Hook, M., & Brownson, R. C. (2017). *The Conceptual Basis*

for Dissemination and Implementation Research: Lessons from Existing Models and Frameworks. Retrieved from

<http://www.oxfordscholarship.com/view/10.1093/oso/9780190683214.001.0001/oso-9780190683214-chapter-5>

Taylor, J., Lambeth, P. F., & Lives, S. O. (2007). *We are not stupid*. People First

Lambeth/Shaping Our Lives.

Tetroe, J. M., Graham, I. D., Foy, R., Robinson, N., Eccles, M. P., Wensing, M., ...

Grimshaw, J. M. (2008). Health research funding agencies' support and promotion of knowledge translation: An international study. *The Milbank Quarterly*, 86(1), 125–155.

<https://doi.org/10.1111/j.1468-0009.2007.00515.x>

The Improved Clinical Effectiveness through Behavioural Research Group. (2006). Designing

theoretically-informed implementation interventions. *Implementation Science*, 1, 4.

<https://doi.org/10.1186/1748-5908-1-4>

The Money, Friends and Making Ends Meet Research Group, United Kingdom. (2012).

Having friends-they help you when you are stuck. From money, friends and making ends meet research group. *British Journal of Learning Disabilities*, 40(2), 128-133.

The SURE Collaboration. (2011). SURE guides for preparing and using evidence-based policy briefs. Retrieved February 4, 2016, from <http://global.evipnet.org/SURE-Guides/>

Thomas, J., & Harden, A. (2008). Methods for the thematic synthesis of qualitative research in systematic reviews. *BMC Medical Research Methodology*, 8(45). doi:10.1186/1471-2288-8-45

Thompson, L., & Rose, J. (2011). Does organizational climate impact upon burnout in staff who work with people with intellectual disabilities? A systematic review of the literature. *Journal of Intellectual Disabilities*, 15(3), 177–193.
<https://doi.org/10.1177/1744629511419616>

Uman, L. S. (2011). Systematic Reviews and Meta-Analyses. *Journal of the Canadian Academy of Child and Adolescent Psychiatry*, 20(1), 57–59.

Ungar, M., McGrath, P., Black, D., Sketris, I., Whitman, S., & Liebenberg, L. (2015). Contribution of participatory action research to knowledge mobilization in mental health services for children and families. *Qualitative Social Work: Research and Practice*, 14(5), 599–615. <https://doi.org/10.1177/1473325014566842>

United Nations. (2006). Convention on the rights of persons with disabilities. Retrieved May 28, 2017, from United Nations website:
<http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf>

University of Minnesota. (2019). *Different Types of Evaluation*. Retrieved October 26, 2019, from Children, Youth, and Families At-Risk website: <https://cyfar.org/different-types-evaluation>

University of York, & NHS Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: CRD, University of York.

Vakola, M. (2013). Multilevel readiness to organizational change: A conceptual approach. *Journal of Change Management*, 13(1), 96–109.
<https://doi.org/10.1080/14697017.2013.768436>

Valor & Solutions. (2017). Home. Retrieved May 7, 2019, from Valor & Solutions website: <https://valorsolutions.ca/en/>

Walter-Brice, A., Cox, R., Priest, H., & Thompson, F. (2012). What do women with learning disabilities say about their experiences of domestic abuse within the context of their intimate partner relationships? *Disability & Society*, 27(4), 503-517.

Ward, K. M., Bosek, R. L., & Trimble, E. L. (2010). Romantic relationships and interpersonal violence among adults with developmental disabilities. *Intellectual and Developmental Disabilities*, 48(2), 89-98.

Ward, V. (2017, August). Why, whose, what and how? A framework for knowledge mobilisers *Evidence & Policy*, 13(3), 77-497.
<https://doi.org/info:doi/10.1332/174426416X14634763278725>

- Ward, V., House, A., & Hamer, S. (2009, August). Knowledge brokering: The missing link in the evidence to action chain? [Text].
<https://doi.org/info:doi/10.1332/174426409X463811>
- Weafer, J. A. (2010). Chapter two – The views and experiences of people with intellectual disabilities. In *Independent and community living: Focus group consultation report*. Obtained from: <http://nda.ie/Publications/Social-Community/Independent-and-Community-Living-Focus-Group-Consultation-Report/Chapter-Two-The-views-and-experiences-of-people-with-intellectual-disabilities/>
- Weisz, C., & Quinn, D. M. (2018). Stigmatized identities, psychological distress, and physical health: Intersections of homelessness and race. *Stigma and Health*, 3(3), 229–240.
<https://doi.org/10.1037/sah0000093>
- Wensing, M., Bosch, M., & Grol, R. (2013). Determinants of change. *Improving Patient Care*.
<https://doi.org/10.1002/9781118525975.ch8>
- Wensing, M., Fluit, C., & Grol, R. (2013). Educational strategies. In R. Grol, M. Wensing, M. Eccles, & D. Davis (Eds.), *Improving Patient Care* (pp. 197–209).
<https://doi.org/10.1002/9781118525975.ch12>
- Werner, K., Horner, R. H., & Newton, J. S. (1997). Reducing structural barriers to improve the social life of three adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 22(3), 138–150.
- Western, J., McCrea, R., & Stimson, R. (2007). Quality of life and social inclusion. *International Review of Sociology—Revue Internationale de Sociologie*, 17(3), 525-537.

- Wheeler, P. (2007). 'I count myself as normal, well, not normal, but normal enough. Men with learning disabilities tell their stories about sexuality and sexual identity. *Tizard Learning Disability Review*, 12(1), 16-27.
- Wholey, J. S., Hatry, H. P., & Newcomer (Eds.). (2010). *Handbook of Practical Program Evaluation* (3rd ed.). San Francisco, CA: John Wiley & Sons.
- Wood, S., Gangadharan, S., Tyrer, F., Gumber, R., Devapriam, J., Hiremath, A., & Bhaumik, S. (2014). Successes and challenges in the implementation of care pathways in an intellectual disability service: Health professionals' experiences: Care pathways: Successes and challenges. *Journal of Policy and Practice in Intellectual Disabilities*, 11(1), 1–7. <https://doi.org/10.1111/jppi.12063>
- World Health Organization. (1992). *The ICD-10 classification of mental and behavioural disorders: clinical descriptions and diagnostic guidelines*. Geneva: World Health Organization.
- World Health Organization. (2016). 6A00 Disorders Of Intellectual Development. Retrieved April 30, 2019, from GCP Network website: <http://pre.gcp.network/en/icd-11-guidelines/categories/disorder/disorder-of-intellectual-development>
- Worton, S. K., Loomis, C., Pancer, S. M., Nelson, G., & Peters, R. D. (2017). Evidence to impact: A community knowledge mobilisation evaluation framework. *Gateways: International Journal of Community Research and Engagement*, 10, 121–42–121–42. <https://doi.org/10.5130/ijcre.v10i1.5202>
- Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: A qualitative study. *British Journal of Learning Disabilities*, 37(1), 5-11.

Yau, M. K., Ng, G. S., Lau, D. Y., Chan, K. S., & Chan, J. S. (2009). Exploring sexuality and sexual concerns of adult persons with intellectual disability in a cultural context. *British Journal of Developmental Disabilities*, 55(109), 97-108.

Appendices

Appendix A: Chapter 2 Figures Explaining Search Process and Reasons for Article Exclusion

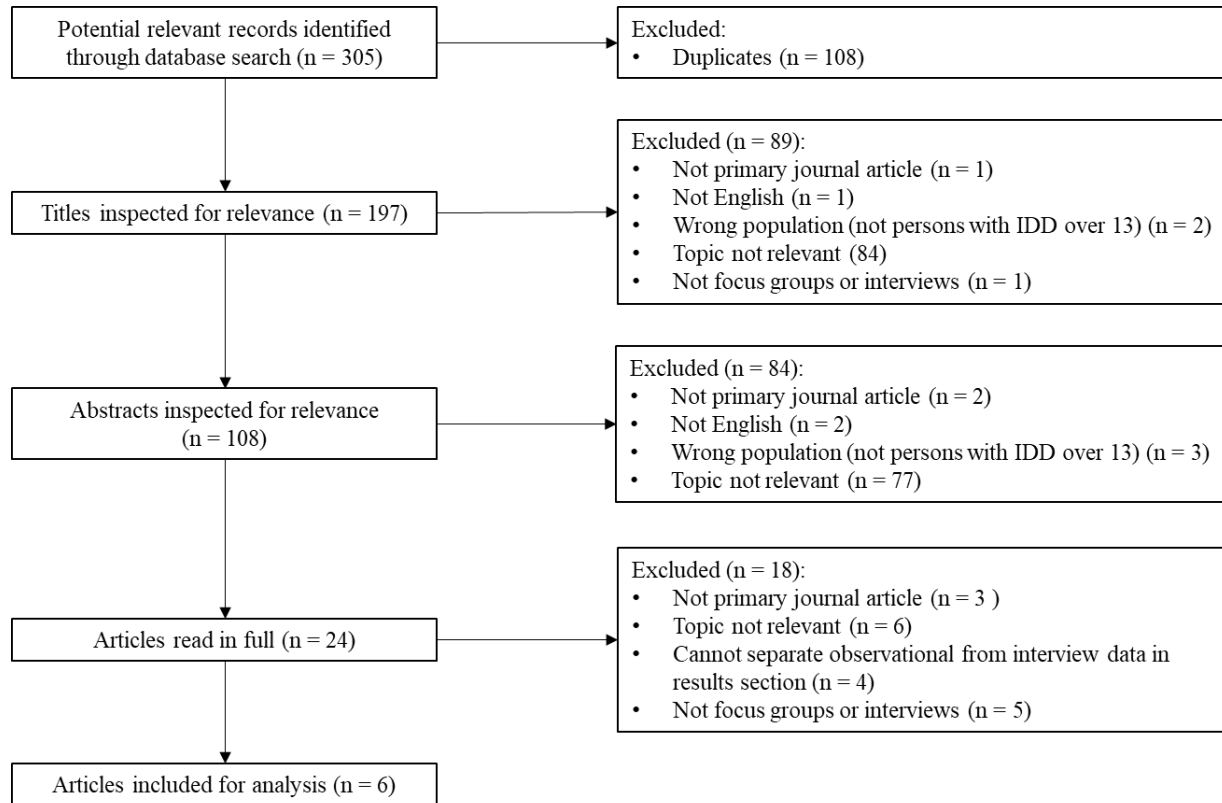


Figure A.1. Systematic online friendship database literature search findings and reasons for article exclusion.

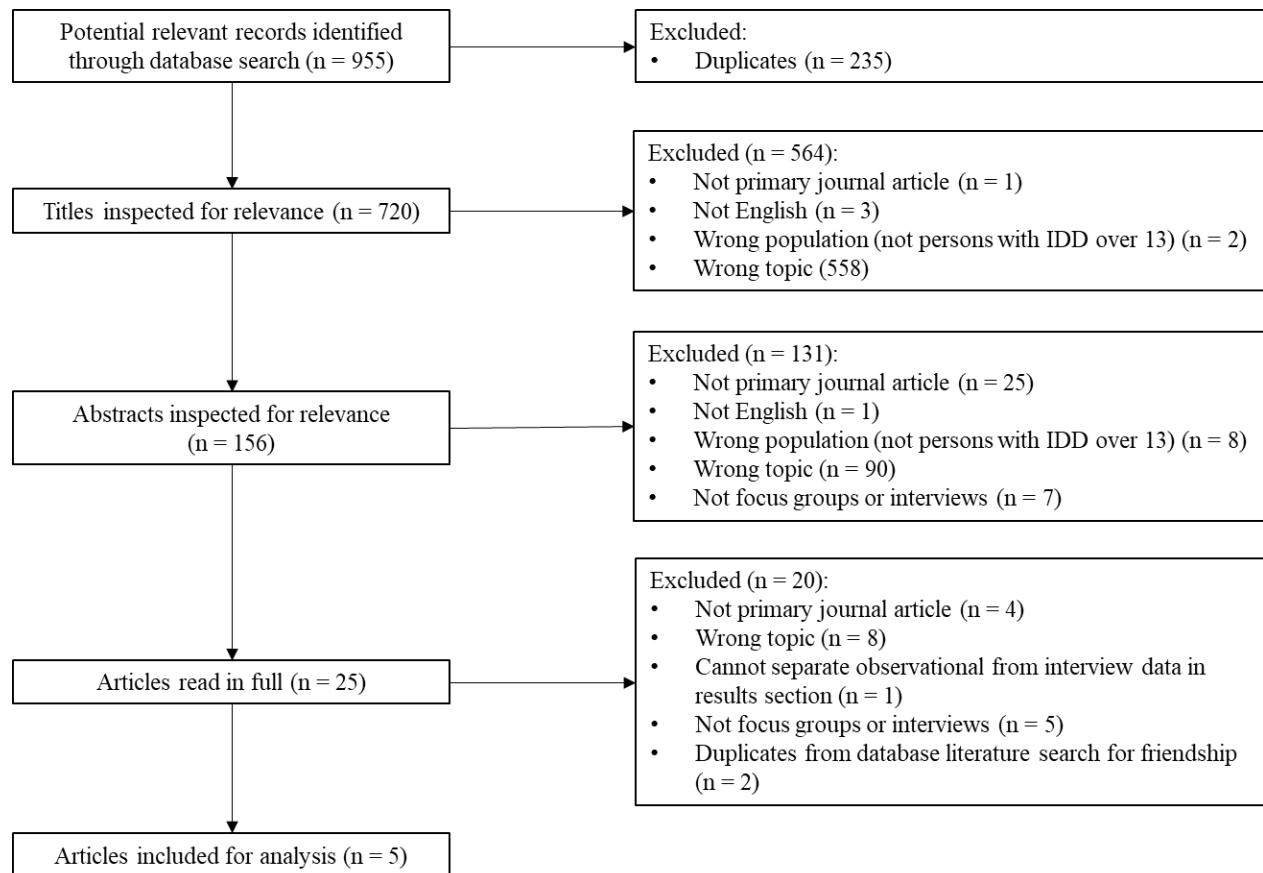


Figure A.2. Systematic online intimate relationship database literature search findings and reasons for article exclusion.

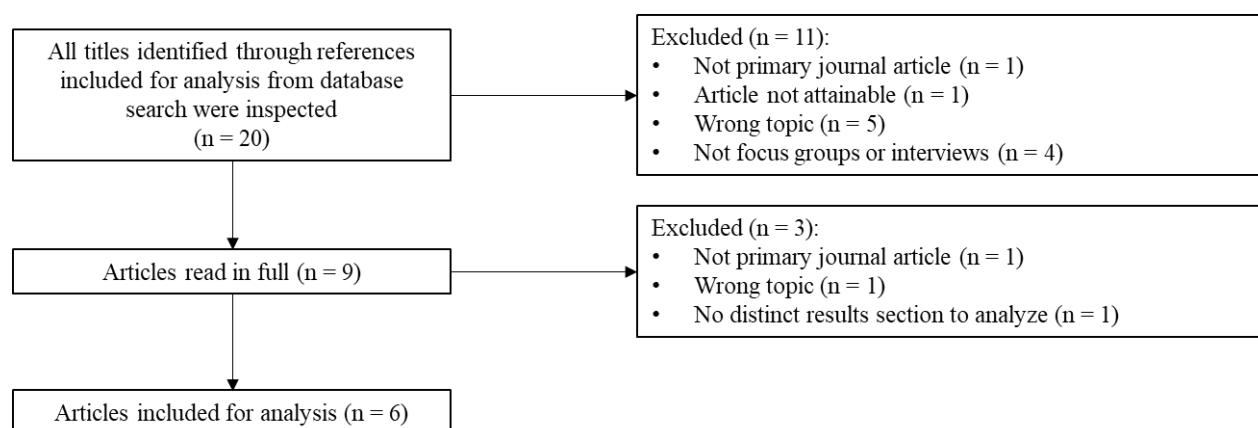


Figure A.3. Friendship and intimate relationship hand search findings and reasons for article exclusion.

Appendix B: Mixed Methods Appraisal Tool (MMAT)

(Pluye et al., 2011)

Types of mixed methods study components or primary studies	Methodological quality criteria (see tutorial for definitions and examples)	Responses			
		Yes	No	Can't tell	Comments
Screening questions (for all types)	• Are there clear qualitative and quantitative research questions (or objectives*), or a clear mixed methods question (or objective*)?				
	• Do the collected data allow address the research question (objective)? E.g., consider whether the follow-up period is long enough for the outcome to occur (for longitudinal studies or study components).				
	<i>Further appraisal may be not feasible or appropriate when the answer is 'No' or 'Can't tell' to one or both screening questions.</i>				
1. Qualitative	1.1. Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?				
	1.2. Is the process for analyzing qualitative data relevant to address the research question (objective)?				
	1.3. Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?				
	1.4. Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?				
2. Quantitative randomized controlled (trials)	2.1. Is there a clear description of the randomization (or an appropriate sequence generation)?				
	2.2. Is there a clear description of the allocation concealment (or blinding when applicable)?				
	2.3. Are there complete outcome data (80% or above)?				
	2.4. Is there low withdrawal/drop-out (below 20%)?				
3. Quantitative non-randomized	3.1. Are participants (organizations) recruited in a way that minimizes selection bias?				
	3.2. Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?				
	3.3. In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?				
	3.4. Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?				
4. Quantitative descriptive	4.1. Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?				
	4.2. Is the sample representative of the population understudy?				
	4.3. Are measurements appropriate (clear origin, or validity known, or standard instrument)?				
	4.4. Is there an acceptable response rate (60% or above)?				
5. Mixed methods	5.1. Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?				
	5.2. Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?				
	5.3. Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?				
	<i>Criteria for the qualitative component (1.1 to 1.4), and appropriate criteria for the quantitative component (2.1 to 2.4, or 3.1 to 3.4, or 4.1 to 4.4), must be also applied.</i>				

*These two items are not considered as double-barreled items since in mixed methods research, (1) there may be research questions (quantitative research) or research objectives (qualitative research), and (2) data may be integrated, and/or qualitative findings and quantitative results can be integrated.

Appendix C: Focus Group Protocol for Service-Users and Family Caregivers

Note: “You” and “your” are highlighted throughout the protocol. For the caregiver focus group, these will be replaced with “the person you support.”

SCRIPT

Introduction (10 min)

1) WELCOME

Hello, my name is _____ and I am a researcher from _____. This is _____. He/she will be helping me with the activities we will be doing. Thank you very much for coming today.

2) BASIC INFORMATION

Before we start, I’m going to tell you about what we will be doing. We are doing research on friendships. We want to know what things get in the way of **your** friendships. Your answers will be used to help the staff at _____ (*name of service agency*) to better support **you**.

We will be doing a focus group today. A focus groups is a group discussion about your thoughts and experiences. There are no right or wrong answers. Everyone’s experiences and opinions are important. Even if you have different opinions than other people in the group, we would like to hear them.

We will be recording the discussion today. The recorders are there (*point to recorders*). We will turn them on if you decide to participate in the discussion. We will record the discussion so that we can listen back to make sure we remember all the information you tell us.

In the report that we write up, we will not include your names; no one reading the report will know that you participated in this talk. We will also share your ideas at a bigger meeting with staff. You will be invited to come to that meeting as well. No one at that meeting will know exactly what you say today, unless you choose to tell them.

Do you have any questions?

If you have questions at any time, please let me know.

3) CONSENT

- *Hand out two copies of the consent forms to each participant*
- *Provide overview of information on the consent form and provide time for participants to read over it*

- *Answer any questions participants have*
- *Emphasize the participants' rights to not answer any questions and drop out at any time*
- *Obtain written consent*

4) FOCUS GROUP INSTRUCTIONS

The following will be said while showing the 'Instructions' chart paper:

Here are some instructions to follow while being part of the group discussion today.

1. *One person speaks at a time.*
 - We ask that only one person speak at a time. Please take turns when talking and don't talk over each other.
2. *Be respectful of other group members, even if you have a different opinion.*
 - We expect that you will not all have the same experiences or opinion. If you do not agree with someone, we want to know that. But please be respectful of the other group members throughout the discussion.
3. *Do not talk to anyone else outside of the group about other group member's personal information.*
 - Please do not talk to people outside the group about what the other group members say or what other group members' names are.
4. *Tell the group if you do not understand something that is said.*
 - If something is not clear, ask for help to understand better.

Also, I ask that you please turn your cell phones to silent and not get up during our discussion. We will have a break in about half an hour. At that time you can go to the bathroom or get more snacks if you want. Our discussion will end at ____ (1 hr and 10 min)

Are there any other rules that you would like to add? Does everyone agree with these new rules?

DISCUSSION AND ACTIVITY (1 hour)

We will now turn on the recorders. (*Administrator – turn on audio recorders*)

Discussion Question 1 (25 min): Quality of support received

As I said before, we are doing research on friendships. We want to know what things get in the way of **your** friendships. Your answers will be used to help the staff at _____ (name of service agency) to better support you.

- What are staff/the agency doing to help **you** make new friends? What do the staff do to help **you** keep **your** friends?
 - For example, are there activities to make new friends? Are there activities to do with friends? Programs? Rules?
 - What about this is helpful?
- Does the staff/agency do anything to make it hard for **you** to make new friends? Do the staff/agency make it hard for you to keep existing friends?
 - What about this makes it difficult?
- Is there anything that you wish _____ (agency) would stop doing?
- What else would you like _____ (agency) to do to help **you** make new friends?
- What else would you like _____ (agency) to do to help **you** see your friends?
- Is there anything that **your** friends at _____ (agency) might want staff to do to help them make friends?

Probes:

- Can you give me an example?
- Please describe what you mean.
- Would you explain further?
- Would you say more?

Do you have any other comments about the help you receive about making and keeping friends?

Activity 1 (30 min): Pile and sort activity

(NOTE: This activity was not effective with the service-users of the first focus group, so instead we verbally described the strategies and then asked the follow-up questions below.)

Here are cards with different strategies to support friendships. *(Each card will have an image and a description. Explain what each card means. Then provide set of cards to each participant, along with a green, yellow, and red marker.)* On your own, please decide if you think the strategies are good, bad, or in the middle. If you think it is a good idea, put a green mark. If you think it is a bad idea, put a red mark. If you are unsure put a yellow mark. There are no right or wrong answers. You get to decide what color the cards should be. You don't have to choose one colour to be green, one to be yellow, and one to be red; the cards can be any colour you choose. For example, all three could be yellow.

I'd like to see which cards were green. Let's go around the table. Please show us your green cards. Please tell me one reason why you think that is a good idea

(Administrator - write the cards and rationales for each participant on the chart paper)

I'd like to see which cards were red. Let's go around the table. Please show us your red cards. Please tell me one reason why you think that is not good idea

(Administrator - write the cards and rationales for each participant on the chart paper)

Facilitator – follow-up questions to ask the group:

- Are there any strategies on the cards that _____ *(name of agency)* already does?
- Which green card is your favorite idea? Why?
- Can you think of any other strategies that would be helpful for supporting friendships?
 - Research findings suggest that _____ *(strategies listed in evidence brief)* is helpful for supporting friendships. How could _____ *(agency)* start doing this strategy?
 - Is there something already in place at _____ *(agency)* that can help with this?
(Determining if there are things in place in the agency that will facilitate strategy implementation)
 - Is there something in place at _____ *(agency)* that would stop this from happening?
(Determining if there are things in place in the agency that will hinder strategy implementation)

Do you have any other comments about these strategies?

6) CLOSING REMARKS (5 min)

_____ *(administrator)* took some notes during our talk. Here are some of the key ideas that I am going to share during the next meeting.

Do you think that those are the key points from our discussion? Is there anything I should add?

Thank you very much for sharing your thoughts with us.

Do you have anything else you want to share with the group?

Do you have any questions?

Appendix D: De-identified Evidence Brief

**Exploring strategies to support friendships for
adults with intellectual disabilities: An evidence
brief for community-based service agencies**

Date: January 29th, 2018

© Casey Fulford, Virginie Cobigo, & Madelaine Ressel

This evidence brief was developed as a research document for Casey Fulford's doctoral dissertation, at the University of Ottawa.

Authors

Casey Fulford, BScH, University of Ottawa, School of Psychology

Virginie Cobigo, PhD, C.Psych., Associate Professor, University of Ottawa, School of Psychology

Madelaine Ressel, BA, University of Ottawa, School of Psychology

Acknowledgements

This evidence brief was prepared using templates and information provided by Supporting the Use of Research Evidence Guides for Preparing and Using Evidence-Based Policy Briefs (The SURE Collaboration, 2011). We would like to thank the members of the focus groups (adults with intellectual disabilities and their family members) who provided input on this evidence brief.

Suggested citation

Fulford, C., Cobigo, V. & Ressel, M. (2017). *Exploring strategies to support friendships for adults with intellectual disabilities: An evidence brief for community-based service agencies* (unpublished report). University of Ottawa, Ottawa, Ontario.

Purpose of this evidence brief

The purpose of the following evidence brief is to inform decisions among key stakeholders. It summarizes the best available strategies in the existing research for supporting the friendships of adults with intellectual disabilities. It is not intended to recommend or exclude specific strategies. Rather, the purpose is to facilitate a discussion in which stakeholders can thoroughly consider the available research on strategies to support the friendships of adults with intellectual disabilities.

How this report was prepared

We conducted a review of existing research to gather information on strategies to support friendships for individuals with intellectual disabilities. We supplemented this information with feedback provided by adults with intellectual disabilities who receive services from a community-based agency, as well as their family members.

Limitations of this Report

This evidence brief is based largely on existing researched articles that focused on strategies for supporting friendships for individuals with intellectual disabilities. Summarizing research requires decisions about what information to include, how to evaluate the quality of the research, and how to report the research findings. Although we attempted to be explicit about the steps used in the development of the evidence brief, this report inherently includes judgements made by the authors.

The Problem

Importance of Friendships

Adults with intellectual disabilities consistently report that making friends and participating in activities with friends is among their most important concerns (Brackenridge & McKenzie, 2005; Cummins & Lau, 2003; Emerson & McVilly, 2004; Knox & Hickson, 2001; Mason, Timms, Hayburn, & Watters, 2013; Weafer, 2010). Although many people with intellectual disabilities are physically integrated in their communities, most remain socially isolated with very few friends (Abbott & McConkey, 2006; Cobigo, Ouellette-Kuntz, & Lysaght, 2012; Lippold & Burns, 2009; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006a). Compared to those without intellectual disabilities, they have fewer social contacts (Department of Health, 2001), are less likely to receive social support, and report higher levels of loneliness (Gilmore & Cuskelly, 2014; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006a). Given their desire for friendship, and the negative impact of social isolation among people with intellectual disabilities, friendship development and maintenance is a key concern for services that provide support to these individuals (McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b). If we are to promote an inclusive society and enhance the quality of life of individuals with intellectual disabilities, their aspirations for friendships must be supported effectively (Emerson & McVilly, 2004).

Barriers to Friendships

Rewarding social relationships do not flow from mere community presence (Knox & Hickson, 2001). Adults with intellectual disabilities require opportunities to engage in meaningful relationships and expand and strengthen their social networks (Asselt-Govers, Embregts, Hendriks, & Frielink, 2014; Ward, Atkinson, Smith, & Windsor, 2013). Both paid and unpaid caregivers play a critical role in supporting friendships for many individuals with intellectual disabilities. However, limited time, money, and resources can interfere with caregivers' ability to provide the support desired by individuals with intellectual disabilities, preventing many of them from seeing their friends as much as they would like (Asselt-Govers et al., 2014; Bane et al., 2012; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b). In addition, caregivers are often concerned about their safety and may restrict privacy and choice-making as a result (Abbott & McConkey, 2006; National Institute for Intellectual Disability, 2009; Money, Friends and Making Ends Meet Research Group, 2012; Ward et al., 2013). These barriers lead to fewer opportunities to form new friendships and maintain existing friendships (Brackenridge & McKenzie, 2005; Lippold & Burns, 2009).

Role of Community Service Agencies

Individuals with intellectual disabilities require practical, informational, and emotional support to develop and maintain friendships (Inclusive Research Network, 2010; McVilly, Stancliffe, Parmenter, & Burton-Smith, 2006b), and many say they require support from staff to have friendships (Inclusive Research Network, 2010). Community-based agencies that support individuals with intellectual disabilities play a crucial role in meeting their friendship-related support needs. Service agencies can provide practical support by offering physical spaces where individuals can spend time with one another (Mason et al., 2013). Regarding informational support, staff can provide guidance on topics such as how to use the internet to stay in touch with

friends (Asselt-Goverts et al., 2014) and using public transit to visit friends (Weafer, 2010). When individuals with intellectual disabilities require emotional support, staff can provide guidance and/or encourage and assist service-users to contact members of their social network (Asselt-Goverts et al., 2014).

Although service agencies provide opportunities and support for socializing, helping individuals with intellectual disabilities develop and maintain friendships remains a challenge (Mason et al., 2013). Barriers include lack of training, resources, and support provided to staff (Abbott & McConkey, 2006; Asselt-Goverts et al., 2014; McConkey & Collins, 2010). Staff must also follow agency policies and manage their concerns regarding service-users' safety, which may further limit opportunities to engage in meaningful relationships (Asselt-Goverts et al., 2014; Finlay, Walton, & Antaki, 2008; Weafer, 2010). Although a number of interventions to support friendships have been implemented for individuals with intellectual disabilities, many programs do not achieve their initial goals (Heslop, 2005).

Strategies to Support Friendships

Literature Review

A literature review of existing research was conducted to obtain information on strategies for supporting friendships for individuals with intellectual disabilities. (Contact the corresponding author for information on the methods used to conduct the literature review.) The level of evidence and quality of the included articles were assessed, and ultimately the highest quality articles were included in this report. The level of evidence was assessed using the Hierarchy of Study Designs to Assess the Effects of Interventions (University of York & NHS Centre for Reviews and Dissemination, 2009). The level of evidence indicates the strength of the results found in a research study, based on the methods used in a study (see below for details). When comparing the levels assigned to different studies, lower numbers indicate that the results are stronger, which means that there is a higher likelihood that the results are due to the strategy that was implemented, rather than something else.

Summary of Levels of Evidence

Level 1 - Randomised controlled trials: Random assignment is a technique for assigning participants to different groups in an experiment. For example, participants could be assigned to group 1 (the group that receives the strategy being tested) or group 2 (the group that does not receive the strategy) using a chance procedure, such as flipping a coin. This strategy helps ensure that similar types of people do not all end up in one group (e.g., all the participants who sign up for the study earlier are not all assigned to group 1).

Level 2 - Quasi-experimental studies: Studies do not use random assignment to create the comparison groups. For example, people may be assigned to groups based on their locations (in this scenario, differences in location could affect the results of the study). Alternatively, the same group of people could be assessed before and after a strategy was implemented; there would be no comparison group.

Level 3 - Observational studies: Groups are not assigned/created; there is natural variation in the strategies being implemented, and the effects of the intervention are evaluated.

Focus Group Findings

Seven adults with intellectual disabilities and eight family caregivers participated in focus groups in May 2017. These participants were recruited through a community-based service agency that provides friendship support for individuals with intellectual disabilities. In these focus groups we presented the strategies included in this evidence brief and asked for participant opinions about the strategies, and for participant suggestions for strategy implementation. Detailed information on each friendship support strategy obtained through the literature review is presented. Summaries of the focus group findings are presented with each strategy. It is important to consider the perspectives of adults with intellectual disabilities and family caregivers when implementing or adapting strategies to support friendships, to ensure that the goals of the program or strategy align with service-user needs.

Factors to Consider when Selecting a Strategy

When considering a strategy or combination of strategies for supporting friendships for people with intellectual disabilities to be adapted and/or implemented at a community-based support agency, it is important to think about barriers and facilitators to effective implementation. See below for factors that could affect strategy implementation (adapted from The SURE Collaboration, 2011), and suggestions for ways in which strategies could be modified:

Strategy Recipients – Adults with intellectual disabilities (and family members)

- Knowledge, abilities, and level of support needs: It is important to consider if implementation of a strategy goes beyond the capacity of service-users, or if the strategy was designed for individuals who require more support. **If the strategy does not align with the capabilities of the service-users (and their caregivers), consider whether the strategy can be adapted to match their abilities. If so, it will be very important to consider feedback from service-users and their caregivers about how to best adapt the strategy.**
- Attitudes about the strategy: Service-users and their family members likely have unique opinions about friendships for individuals with intellectual disabilities and the proposed strategies. It is therefore important to consider their opinions as much as possible when selecting a strategy. **If decisions are made that are not in line with the views of service-users and their families it will be important to explain why certain decisions were made (e.g., a suggestion was not feasible due to limited resources).**
- Motivation to engage in strategy activities: It is likely that service-users and their caregivers will vary in their level of motivation to participate in the activities associated with each strategy. However, because service-users have likely sought out services due to an existing need/desire, it is expected that most will be motivated to participate. **If they exhibit a lack of motivation, it will be useful to explore why this is the case, so that the strategy can be**

adapted to increase participants' desire to participate.

Strategy Providers – Agency staff members (and volunteers)

- Knowledge and skills: Agency staff members likely have varying knowledge and experience in supporting friendships for individuals with intellectual disabilities. **It will be important to select individuals with the requisite knowledge and skills (or the ability and motivation to gain the knowledge and skills) to implement a given strategy.**
- Attitudes about the strategy: Agency staff will inevitably have opinions about the strategy being implemented. It is therefore important that all staff members are given the opportunity to voice their opinions and that all opinions are considered when selecting a strategy. **If strategy selection decisions are made that conflict with the views of some staff, it will be important to discuss the reasons behind these decisions.**
- Motivation to implement strategy: It is likely that staff will vary in their level of motivation to develop and engage in the activities associated with each strategy. **It is suggested that individuals who are more motivated to change friendship support practices take the lead on implementing a strategy.**

Constraints of the Organization

- Financial resources: The service agency may not have the finances required to implement a given strategy. **If it is not possible to obtain the funds to implement a strategy, the agency staff members could aim to revise or streamline the strategy to reduce costs.**
- Human resources: Agency staff may not have enough time to fully implement a strategy. **If this is the case, staff could consider obtaining assistance/support from volunteers who are already affiliated with the agency, or recruiting new volunteers to be involved in the project.**
- Decision making: Individuals involved in implementation of a strategy may be required to make decisions beyond those associated with their typical role. **This may necessitate a discussion with management regarding the scope of decision making power.**
- Regulations: Organizational policies may hinder strategy implementation. **If this is the case, the agency may consider adapting policies to allow for the implementation of the strategy. Alternatively, the strategies could be adapted to align with policies.**

It is important to keep the above factors in mind when considering research findings on different friendship support strategies and the strategy-specific feedback provided by adults with intellectual disabilities and their family caregivers.

Strategy 1: Befriending Scheme

Source: Hughes, A., & Walden, S. (1999). Befriending: A note of caution. *British Journal of Learning Disabilities*, 27, 88-92.

Level of Evidence: 2

Description of Participants:

<u>Individuals with intellectual disabilities:</u>	<u>Volunteers:</u>
• $n = 4$ • Age: Range = 30-60 • Gender: F = 25%, M = 75% • Living arrangements: participants lived in a group home where they received 24-hour support.	• $n = 10$ • no other information provided

Strategy Description:

This is a strategy for increasing the social networks of people with intellectual disabilities living in supported housing. A “befriending agency” recruited volunteers through advertising in a local newspaper and interviewed interested volunteers. Volunteers without intellectual disabilities were paired with a group home where individuals with intellectual disabilities lived. They were expected to visit on a regular basis, over a 4 month period. Multiple volunteers were assigned to spend time with each individual with intellectual disabilities. Volunteers were expected to help individuals with intellectual disabilities increase the frequency of contact and size of their social networks by introducing them to new people and activities in the community.

Volunteers received a 2-day group training, and on-going support was offered to volunteers by means of 2-hour facilitated group meetings on a monthly basis. Training included education about communicating with people with intellectual disabilities, rights and responsibilities of the volunteers, identifying the skill base and social networks of individuals with intellectual disabilities, and brainstorming ways to improve social networks. Group home staff received a half-day training about how to communicate and problem solve with the volunteers, the rights and responsibilities of volunteers, and details about the training that the volunteers received. Weekly meetings were provided for the individuals with intellectual disabilities to prepare them for the arrival of the befriending volunteers. These meetings continued throughout the program to explore how the individuals with intellectual disabilities felt about the program.

Main Findings:

Attitudes towards individuals with intellectual disabilities:

- No information provided.

Impact on individuals with intellectual disabilities:

- Support staff believed that the program facilitated the involvement of individuals with intellectual disabilities in outside activities, enhanced their social skills, and increased their self-esteem.
- However, staff emphasized that new friendships should not be made at the expense of existing friendships and the importance of valuing friendships between people with intellectual disabilities.

Amount of social contact:

- Four months after implementation of the program only 1 volunteer was visiting.
- Frequency of visits from members of social networks increased for 2 individuals with intellectual disabilities and decreased for 2 individuals.

Social network size and composition:

- Social network size increased for 1 individual with intellectual disabilities, stayed the same for 2 individuals, and decreased for 1 individual.

Activities engaged in:

- Overall, the total number of activities participated in increased across participants. However, for 1 participant the number of activities decreased.

Additional considerations:

- There was tension between volunteers and caregivers in the group home; staff found it difficult to coordinate with volunteers.
- Consideration should be given to existing friendships to ensure that these are not replaced by, or suffer, as a result of new relationships.
- There is no additional information available on how to implement this strategy, beyond the content in the published article.

Focus Group Summaries:

Individuals with intellectual disabilities tended to like this strategy. They liked that volunteers would come to their houses and help “guide” them into the community where they can meet new people. This is especially helpful when going to places for the first time. They would like to choose the activities that they do, and they would like volunteers to help support them to do these activities (e.g. registering, orientation, seeing if it’s a good fit). Individuals with intellectual disabilities indicated that the community-based agency would likely need to recruit many additional volunteer to implement this strategy. They thought it would be ideal to have two or

three volunteers assigned to each service-user, because one volunteer would find it too time consuming and would not be able to attend all the desired activities. They indicated that they would like to get together with volunteers every week or every few weeks. Due to lack of consistency with past volunteers, they suggested that agency staff ask volunteers if they are actually committed to consistently spending time with their match.

Caregivers tended to like the idea of having volunteers accompany individuals with intellectual disabilities to do activities in the community, because some service-users require additional support to engage in community activities. In addition, caregivers think it would be a really good idea to have two service-users attend the same activities with a volunteer. Caregivers also would like volunteers who are available at a variety of times (during the day and evening, on weekdays and weekends).

Strategy 2: Australian Supported Learning Program (ASLP) - Me and My Community

Source: McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw, K., & Hindsmarsh, G. (2008). Strengthening the social relationships of mothers with learning difficulties *British Journal of Learning Disabilities*, 37, 66–75.

Level of Evidence: 2

Description of Participants:

All participants were mothers with intellectual disabilities and had at least one child less than 5 years of age. All were able to participate in group discussion. Individuals lived in New South Wales and Victoria, Australia.

Individuals with intellectual disabilities

- $N = 32$
- Age: Mean = 34, Range = 17-48
- Gender: F = 100%
- Ethnicity: Majority were born in Australia (91%)
- Living arrangements: All individuals lived independently in:
 - Owned property = 22%
 - Rented property = 44%
 - Public housing = 34%

Strategy Description:

The aims of this strategy are to make friends, meet new people, and get involved in the community. A *Guide for Facilitators* and a *Participant Workbook* were developed to facilitate the implementation of this program. At the outset of the program, there were 10 specific program goals for which participants indicated their interest in achieving each specific goal (i.e., Meet people and make new friends, Feel more confident about participating in groups, Learn about places I can go to for help, Learn more about places my whole family can go together, Find out where I can go to do things I like doing, Learn more about my own strengths and things I am good at, Learn more about things I can

do to help out in my community, feel more confident about going places in my community, Learn some things that will help me get out, Get more enjoyment out of life). The program involved 8-10 weeks of group work using a problem-posing approach to adult learning. Each week, individuals with intellectual disabilities participated in a 2-hour group work session. Group work was followed by weekly home challenges to encourage participants to reflect on and practice what was discussed in the group. Group work was supplemented by individual support (phone contact and home visits) to assist participants with more specific and personal goals.

Throughout the program, participants worked with a facilitator and the group, to reflect on personal experiences in the community, identify areas for improvement, identify 5 personal community involvement goals, make plans to achieve their goals, and ultimately implement those plans.

This process involved 3 components:

- One aspect of the program involved having participants create a mural of their community to represent challenges in a tangible way; these murals would be used at each group session to help facilitate and focus the discussion topics.
- Another aspect of the program involved participating in a guided 3-step questioning method to tackle challenges together. This questioning technique occurred throughout each group meeting. First participants are asked to describe their experiences, and identify similarities between their experiences. Then participants were asked why they think these experiences occur. Finally, they were requested try and solve these issues in order to reach their goals.
- The final aspect of the program involved engaging in guided action planning. The participants were taught how to break down the strategies into manageable tasks, to achieve their goals.

Main Findings:

Attitudes towards individuals with intellectual disabilities:

- No information provided.

Impact on individuals with intellectual disabilities:

- 84% of individuals achieved their first priority personal goal.
- Each program goal was partially or fully achieved by at least 90% of participants.
- Between 16% and 59% of participants felt they had not fully achieved each individual program goal (i.e., for each goal, at least 16% of participants wanted to keep working on fulfilling the program goal).
- Overall, participant scores of depression decreased and social support scores increased.
- Following the program, participants were more confident about getting involved in their communities, were more aware of opportunities and resources in their communities, and some were even inclined to take advantage of these opportunities by joining groups and classes within their communities.

Amount of social contact:

- No information provided.

Social network size and composition:

- No information provided.

Activities engaged in:

- No information provided.

Additional considerations

- The program was run by family support professionals who were experienced group work facilitators with qualifications in psychology and/or social welfare.
- The dynamics between participating individuals was important for success of program.
- The researchers have obtained additional information which can be used to inform implementation of this strategy. This includes a report containing staff opinions about the strategy, the facilitator guide, and the participant scrapbook.

Focus Group Summaries:

Service-users had very mixed feelings about this strategy. Some individuals with intellectual disabilities expressed reluctance at meeting every week; they thought this may be difficult to plan and commit to as they said they are usually very busy during the week. However, others indicated that they would be available and would like to do this. Some service-users also had some concerns about meeting at the same place every week because it might be hard for some people to get to. Some individuals also felt as though this strategy offered too much involvement and one-on-one help from staff. They indicated that this strategy would take away their independence and they do not want to be monitored so closely. However, others really liked the idea of having more involvement from staff and being closely monitored.

Similarly, caregivers thought this strategy would work very well for some individuals but not so well for others. Some caregivers thought that their children would not be able to develop individual goals, because they have limited interests, or do not have a good conception of what their true interests are. However, they think that service-users would still enjoy coming to spend time with a group on a weekly basis, because it would be a social activity. Other caregivers thought this strategy could help service-users develop more independence. It could also show them that others have similar social difficulties and have social goals as well.

Given some instances of bullying in the past, and difficulties with differing personalities of service-users, caregivers thought the success of this strategy would depend on the group dynamics. They would want agency staff members to consider who the group participants would be and think about how they might interact with one another. Caregivers also thought that these workshops should be offered on multiple days of the week, so that individuals who have weekly commitments can have different options for attending the workshops.

Strategy 3: Best Buddies College Program

Source: Hardman, L., & Clark, C. (2006). Promoting friendships through Best Buddies: A national survey of college program participants. *Mental Retardation*, 44(1), 56-63.

Level of Evidence: 3

Description of Participants: All participants lived in the United States; the majority in California, Florida, and Texas. All individuals were able to answer survey questions verbally or in writing.

<u>Individuals with intellectual disabilities:</u>	<u>Volunteers:</u>
• $n = 1,145$ • Age: Mean = 32, Range = 12-78 • Gender: F = 51%, M = 48%, unknown = 1% • Ethnicity: primarily Caucasian (69%)	• $n = 1,222$ • Age: Mean = 20, Range = 17-51 • Gender: F = 80%, M = 17%, unknown = 3% • Ethnicity: primarily Caucasian (76%)

Strategy Description: This is a strategy to foster friendships between individuals with and without disabilities. The Best Buddies College Program facilitated one-to-one friendships between college students without disabilities and individuals with intellectual disabilities. College/university students who were interested in volunteering submitted applications (which included a survey about their personality and interests) and underwent an interview by Best Buddies staff. Partners (volunteers and individuals with intellectual disabilities) were matched based on common interests and personalities. For the duration of one year, volunteers committed to: a) contacting their partner on a weekly basis (phone call, letter, e-mail, or in-person), b) having a one-on-one activity with their partner 2-3 times each month, and c) attending Best Buddies chapter meetings and group activities.

Main Findings:

Attitudes towards individuals with intellectual disabilities:

- 80% of volunteers had more positive attitudes about the abilities of people with intellectual disabilities.

Impact on individuals with intellectual disabilities:

- Over 40% of individuals with intellectual disabilities were more comfortable in social settings, speaking up for themselves, and participating in the community.
- 60% of individuals with intellectual disabilities said making friends in the program had enhanced their lives.
- 80% of partners enjoyed the program and would participate again.

Amount of social contact:

- 50% of partners spoke to each other on the phone at least once per month.
- 78% of volunteers and 71% of individuals with intellectual disabilities participated in either a one-to-one activity or a planned group activity on a monthly basis
- Individuals with intellectual disabilities consistently expressed that they did not see their partners as much as they would like or as much as the program suggested (2-3 outings each month).

Social network size and composition:

- No information provided.

Activities engaged in:

- Friendship: telephone calls, going to movies, eating at restaurants, sporting events, outdoor recreation, spending time together at home

- Teaching: social skills, use of transportation, job skills, and finances

Additional considerations:

- There were differences in expectations between volunteers and individuals with intellectual disabilities with regard to desired frequency of contact; individuals with intellectual disabilities expressed wanting to see their partners more often.
- Partners were often different genders and ages. However, the researchers did not think that this was an issue for the partners involved in the program.
- The researchers have additional information which can be used to inform implementation. This includes the volunteer application survey, an outline of the volunteer training, and additional details regarding logistics of implementation.

Focus Group Summaries:

Adults with intellectual disabilities agreed that this strategy would be a great way to meet new friends. They said that they would get along well with university-aged students because they have similar interests and like to do fun things. Some service-users also felt they might be able to mentor the students involved in this program, because they are older and may know things students do not know. This would help them build a relationship and become friends. Others indicated that it did not matter how old volunteers would be; that they got along with people who were both older and younger than them.

Caregivers thought this was a really good strategy. They liked how consistently and frequently the activities would take place. They also thought their children would enjoy spending time with university-aged individuals, as they tend to connect more easily with young adults compared to older adults. However, caregivers were concerned that volunteers would be unreliable. They thought volunteers may decide that they are uninterested in spending time with service-users, and they also foresaw issues with consistency due to the nature of the annual university schedule (e.g., being less available during exam time).

Strategy 4: Unified Sports

Source: McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through Unified Sports for youth with intellectual disabilities: A five-nation study. *Journal of Intellectual Disability Research*, 57(10), 923-935.

Level of Evidence: 3

Description of Participants:

Individuals were recruited from Unified Sports soccer and basketball teams. All individuals were physically able to engage in sports and were able to respond to questions in interview format. They lived in Europe (Serbia, Poland, Ukraine, Germany, and Hungary).

<u>Athletes with intellectual disabilities</u>	<u>Athletes without intellectual disabilities</u>	<u>Coaches</u>
• $n = 156$ • Age: Range = 12-25 (56% were 16-25) • Gender: F = 19%, M = 81% • Living arrangements: One third lived in institutions or boarding schools, and two-thirds lived with family members.	• $n = 106$ • Age: Range = 12-25 (79% were 16-25) • Gender: F = 13%, M = 87% • Living arrangements: Majority lived with family members.	• $n = 65$ • Gender: F = 25%, M = 75%

Strategy Description:

This is a strategy to develop friendships between young people with and without intellectual disabilities through sports, and provide opportunities for community inclusion of individuals with intellectual disabilities. The Unified Sports program of Special Olympics brought together individuals of a similar skill level on the same sports teams for frequent training and competitions. Individuals were screened to assess their basic skills and ability to play the sport, to ensure that players were well matched in terms of ability. Coaches had detailed knowledge about the rules of the sport, and they were encouraged to take part in coaches training offered by Special Olympics.

The teams trained regularly and competed with other Unified Sports teams at the local, national, and international level. The Unified Sports programs took place in schools, Special Olympics clubs, and sports clubs within the community.

Main Findings:

Attitudes towards individuals with intellectual disabilities:

- Individuals without intellectual disabilities began to respect those with intellectual disabilities more, and began to better recognize their abilities.

Impact on individuals with intellectual disabilities:

- Individuals with and without intellectual disabilities became more confident and comfortable socializing with one another.
- Individuals with intellectual disabilities experienced increased self-confidence and social status among peers in community.
- People with intellectual disabilities experienced improved interpersonal skills (i.e., more confidence, less shyness, stated opinions more, less afraid of strangers).
- Team members were treated as equals by each other and by coaches.
- All participants agreed that the program led to more social inclusion and increased opportunities to engage in community life.

Amount of social contact:

- No information provided.

Social network size and composition:

- No information provided.

Activities engaged in:

- Friendships developed among teammates on and off the field. Teammates engaged in many non-sports activities together.
- When inclusive and equal bonds were less evident amongst athletes with and without intellectual disabilities, there was less joint participation in community settings.

Additional considerations:

- Caregiver support is essential to the success of the program. Caregivers will likely need to provide transportation and financial support.
- Coaches play a major role in facilitating cohesion of team members and encouraging equality.
- Type of sport(s) may affect gender ratios of interested participants.
- If this strategy is selected, there is additional information online which can be used to inform implementation. This includes guidelines for coaches, guidelines on athlete participation, additional research articles about Unified Sports, and general information about the program online.

Focus Group Summaries:

Service-users seemed to agree that aspects of this strategy could work. Although some individuals do not like sports, they might be interested in coming to watch and cheer on the team. Others were very enthusiastic about this strategy because they enjoy playing sports and think it would provide an opportunity to see people more often. At the same time, service-users seemed to think that integrating people with and without disabilities might be difficult to do. Some service-users have tried to join sports teams in the past and they found they were too competitive. They suggested that game rules might have to be changed to accommodate for different types of disabilities and different skills levels. Additionally, service-users indicated that they would like support getting started on sports teams and help going and purchasing equipment.

Caregivers thought the success of this strategy would depend on the makeup of the team; if it would be primarily comprised of individuals with intellectual disabilities then caregivers did not see this strategy as fostering friendships with the wider community. They said a better idea might be to use existing community resources (sports clubs, teams, gyms). However, it would be important to have the service agency work to build (and maintain) bridges within those pre-established services, by introducing people, helping service-users to exchange phone numbers with community members, assisting them in keeping in touch, and planning outings together on a recurring and regular basis. On the other hand, some caregivers indicated that community members may not be accepting of adults with intellectual disabilities. Some caregivers said that a team comprised of volunteers and service-users may be more likely to be long lasting, as volunteers may desire and seek out friendship more with people with disabilities than individuals from the community. Another potential problem with this strategy that caregivers identified was that not all service-users are athletic or enjoy playing sports. They thought that individual sports

that are done as a group may be more appealing to service-users, such as bowling, skiing, skating.

Strategy 5: Barrier Reduction Package

Source: Werner, K., Horner, R. H., & Newton, J. S. (1997). Reducing structural barriers to improve the social life of three adults with severe disabilities. *Research and Practice for Persons with Severe Disabilities*, 22(3), 138-150.

Level of Evidence: 3

Description of Participants: Individuals lived in Oregon, United States.

<u>Individuals with intellectual disabilities:</u>	<u>Staff:</u>
• $n = 3$ • Age: Mean = 33.66, Range = 30-40 • Gender: M = 100% • Living arrangements: Residential support, with at least 2 staff for all 3 individuals, at any given time. • Support level: non-verbal and requiring 24-hour support	• $n = 19$ • Age: Range = 19-44

Strategy Description:

This is a strategy to reduce social barriers for people with intellectual disabilities. Personalized barrier reduction packages were developed based on interviews with support staff, during which they discussed social barriers experienced by individuals with intellectual disabilities. Packages were developed by participants and their support staff.

The barrier reduction packages included the following components. These components were implemented as necessary based on each individual's specific social challenges:

8. Personal schedule: Social activities were noted in a weekly date book.
9. Social activity scheduling: Social activities were planned and marked in individual's personal schedule for the up-coming week at weekly meetings.
10. Personal information sheet: 1-2 page descriptions of the individual with intellectual disabilities, to be used when meeting new people. Included information that 'friends should know', such as birthplace, places lived, names of parents and siblings, activity preferences, personal accomplishments, etc.
11. Friendship form: 1 page of information about people in the community who did activities with participant including their name, address, telephone number, and activities done together.
12. Photo address file: Pictures and information about friends, so that the individual could select who they wanted to contact.
13. Photo activity file: Pictures of different activities, to select and convey preferences.

14. Weekly feedback: Staff wrote weekly summaries about participant social activities and reviewed summaries at weekly meetings.

Support staff were provided with a 1 hour training session about the importance of relationships, the activities that the individuals with intellectual disabilities currently engage in, barriers to social contact, and were provided with an introduction to the barrier reduction package. Over the following 2 weeks the researchers supported the staff to develop the required barrier reduction components (e.g., photo address file and photo activity file), and they provided guidance on how to implement the different components of the package (15-30 minutes per component). Finally, the barrier reduction packages were implemented by support staff, without any further support.

Main Findings:

Attitudes towards individuals with intellectual disabilities:

- No information provided.

Impact on individuals with intellectual disabilities:

- After 6 months, staff had used/implemented at least 6 components of the Barrier Reduction Package.

Amount of social contact:

- No information provided.

Social network size and composition:

- The number of different people with whom activities were engaged in on a weekly basis increased for 2 of the participants.

Activities engaged in:

- The number of social activities engaged in on a weekly basis increased for 2 of the participants.
- All participants started to visit other people at their homes more frequently.
- All participants began engaging in community activities that they had not previously done, such as visiting friends, shopping, running errands and participating in music and leisure events.

If this strategy is implemented, the community-based agency will be responsible for the following activities:

- Obtaining or developing templates for the barrier reduction packages.
- Providing 1-hour meetings with caregivers of individuals with intellectual disabilities, to explain the importance of social relationships, discuss the current social activity patterns of the individual with intellectual disabilities, identify barriers to socialization, and review the barrier reduction strategies
- Assisting caregivers and individuals with intellectual disabilities to develop personalized barrier reduction packages.
 - Providing support on how to use each of the barrier reduction strategy
 - There is no additional information available on how to implement this strategy, beyond the content in the published article.

Focus Group Summaries:

Service-users had mixed feelings about this strategy. Some people thought that writing down the exact time and location of meetings would help them make more concrete plans, as sometimes their plans are not specific enough. However, some also said that they would not consistently use a schedule because they want flexibility in their choice of daily activities. For example, if a friend asks to spend time together last minute or if they feel like having time alone after a long day, they want to be able to do these things. They also said they were uncomfortable with a personal information sheet, because they would not want to share their information with people they did not know. Finally, some service-users indicated that they already have their friends' contact information (or are not interested in contacting their friends via telephone) and do not need this package. However, others would like to be provided with this information.

Caregivers seemed to agree that the success of this strategy would depend on the staff member involved in its implementation. Most thought that a competent and committed staff member, who ensured that planned social activities actually happened and who assisted service-users with making friends at the activities, would be essential to truly foster friendships. Some caregivers felt that changes in staffing could severely disrupt any progress in terms of social integration associated with this strategy. Caregivers indicated that a positive aspect of this strategy would be that social activities could be offered on different days of the week. Other caregivers felt that although the package may increase the amount of social activities service-users are engaged in, unless an individual (either volunteer or staff) is available to facilitate friendship development and maintenance at those activities, true friendship would not be fostered.

References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10(3), 275–287.
- Asselt-Goverts, A. E., Embregts, P., Hendriks, A. H. C., & Frielink, N. (2014). Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology*, 24(2), 111–124.
- Bane, G., Dooher, M., Flaherty, J., Mahon, A., Donagh, P. M., Wolfe, M., ... Shannon, S. (2012). Relationships of people with learning disabilities in Ireland. *Mental Handicap*, 40(2), 109–122. <https://doi.org/10.1111/j.1468-3156.2012.00741.x>
- Brackenridge, R., & McKenzie, K. (2005). The Friendships of People with a Learning Disability. *Learning Disability Practice*, 8(5), 12–17.
- Cobigo, V., Ouellette-Kuntz, H., & Lysaght, R. (2012). Shifting our conceptualization of social inclusion. *Stigma Research and Action*, 2(2), 75–84.
- Cummins, R. A., & Lau, A. L. (2003). Community integration or community exposure? A review and discussion in relation to people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 16(2), 145–157.
- Department of Health, L. (United K. (2001). *Valuing people A new strategy for learning disability for the 21st century: a white paper*. London: Stationary Office.
- Emerson, E., & McVilly, K. (2004). Friendship Activities of Adults with Intellectual Disabilities in Supported Accommodation in Northern England. *Mental Handicap Research*, 17(3), 191–197. <https://doi.org/10.1111/j.1468-3148.2004.00198.x>
- Finlay, W. M. L., Walton, C., & Antaki, C. (2008). Promoting choice and control in residential services for people with learning disabilities. *Disability & Society*, 23(4), 349–360. <https://doi.org/10.1080/09687590802038860>
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Hardman, M. L., & Clark, C. (2006). Promoting friendship through best buddies: a national survey of college program participants. *Mental Retardation*, 44(1), 56–63. <https://doi.org/2>
- Heslop, P. (2005). Good practice in befriending services for people with learning difficulties. *British Journal of Learning Disabilities*, 33(1), 27–33.
- Hughes, A., & Waldenm, S. (1999). Befriending: a note of caution. *British Journal of Learning Disabilities*, 27(3), 88–92.
- Inclusive Research Network. (2010). *Relationships and supports tudy: People with intellectual disabilities in Ireland*. Dublin: Dublin: National Institute for Intellectual Disability Ireland; Galway: National Federation of Voluntary Bodies. Retrieved from http://www.fedvol.ie/_fileupload/Relationships%20and%20Supports%20Report%202010.pdf
- Kersh, J., Corona, L., & Siperstein, G. (2013). Chapter: Social well-being and friendship of people with intellectual disability. In M. L. [Ed] Wehmeyer (Ed.), *The Oxford handbook of positive psychology and disability* (Vols. 1–Book, 1–Section, pp. 60–81). New York,

- NY, US: Oxford University Press; US. Retrieved from <http://sfx.scholarsportal.info/ottawa?sid=OVID:psycdb&id=pmid:&id=doi:&issn=&isbn=0195398785&volume=&issue=&spage=60&pages=60-81&date=2013&title=The+Oxford+handbook+of+positive+psychology+and+disability.&atitle=Social+well-being+and+friendship+of+people+with+intellectual+disability.&aulast=Kersh&pid=%3Cauthor%3EKersh%2C+Joanne%3BCorona%2C+Laura%3BSiperstein%2C+Gary%3C%2Fauthor%3E%3CAN%3E2013-30840-006%3C%2FAN%3E%3CDT%3EChapter%3C%2FDT%3E>
- Knox, M., & Hickson, F. (2001). The meanings of close friendship: The views of four people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 14(3), 276–291.
- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: a comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53(Journal Article), 463–473. <https://doi.org/10.1111/j.1365-2788.2009.01170.x>
- Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities*, 26(2), 108–118. <https://doi.org/10.1111/jar.12001>;
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54(8), 691–700.
- McConkey, R., Dowling, S., Hassan, D., & Menke, S. (2013). Promoting social inclusion through unified sports for youth with intellectual disabilities: a five-nation study. *Journal of Intellectual Disability Research*, 57(10), 923–935.
- McConnell, D., Dalziel, A., Llewellyn, G., Laidlaw, K., & Hindmarsh, G. (2009). Strengthening the social relationships of mothers with learning difficulties. *British Journal of Learning Disabilities*, 37(1), 66–75.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. (2006a). “I Get by with a Little Help from my Friends”: Adults with Intellectual Disability Discuss Loneliness. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 191–203. <https://doi.org/10.1111/j.1468-3148.2005.00261.x>
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006b). Self-advocates have the last say on friendship. *Disability, Handicap & Society*, 21(7), 693–708. <https://doi.org/10.1080/09687590600995287>
- National Institute for Intellectual Disability. (2009). *All we want to say: Life in Ireland for people with intellectual disabilities*. Dublin: Trinity College.
- Money, Friends and Making Ends Meet Research Group (2012). Having friends - They help you when you are stuck. *Mental Handicap*, 40(2), 128–133.
- The SURE Collaboration. (2011). SURE guides for preparing and using evidence-based policy briefs. Retrieved February 4, 2016, from <http://global.evipnet.org/SURE-Guides/>
- University of York, & NHS Centre for Reviews and Dissemination. (2009). *Systematic reviews: CRD's guidance for undertaking reviews in health care*. York: CRD, University of York.
- Ward, K. M., Atkinson, J. P., Smith, C. A., & Windsor, R. (2013). A friendships and dating program for adults with intellectual and developmental disabilities: a formative

- evaluation. *Intellectual and Developmental Disabilities*, 51(1), 22–32.
<https://doi.org/10.1352/1934-9556-51.01.022>;
- Weafer, J. A. (2010). *Chapter Two - The views and experiences of people with intellectual disabilities* (Independent and community living: Focus group consultation report). The National Disability Authority. Retrieved from <http://nda.ie/Publications/Social-Community/Independent-and-Community-Living-Focus-Group-Consultation-Report/Chapter-Two-The-views-and-experiences-of-people-with-intellectual-disabilities/>
- Werner, K., Horner, R. H., & Newton, J. S. (1997). Reducing structural barriers to improve the social life of three adults with severe disabilities. *Journal of the Association for Persons with Severe Handicaps*, 22(3), 138–150.
- Yacoub, E., & Hall, I. (2009). The sexual lives of men with mild learning disability: a qualitative study. *British Journal of Learning Disabilities*, 37(1), 5–11.

Appendix E: Interview Protocol for Interview with Director of Organization

Details:

- Duration: ½ hour
- Location: phone interview

Script:

- *Important consent form information*
 - Reiterate that participation is voluntary
 - Remind that the interview is audio-recorded
- *Research objective*
 - Throughout the research activities we have been evaluating the process of using existing research findings to inform practices to support friendships for individuals with intellectual disabilities.
- *Purpose of interview*
 - We will be asking you about your views related to the research activities leading up to the planned stakeholder dialogue.
 - Your feedback will help us understand how to best adapt the knowledge translation process to meet the needs of community-based agencies.
- *Context*
 - As you know, the research process was stopped a couple days before the stakeholder dialogue was scheduled.
 - We would like to understand and document the study process up until the cancelled stakeholder dialogue, from your perspective. And, we would also like to understand what led to the breakdown in the process.
- *Questions*
 - So let's first focus on the process from February 2017 to October 2017. I met with the advisory committee 5 times over those months.
 - Can you please tell us how the advisory committee was set up? How were decisions made regarding membership?
 - The advisory committee supported me in making decisions regarding recruitment for consultations and the questions asked at consultations. Were these decisions and the findings of the consultations reported to you and OTHER DIRECTOR?
 - How frequently did the advisory committee members report to you and OTHER DIRECTOR about the project?
 - How would you suggest we improve the knowledge mobilization process used during that time?
 - As you know, a few days prior to the stakeholder dialogue, your agency expressed concerns about the purpose of the study.

- Can you tell us what happened once the evidence brief was sent to the advisory committee members?
 - How would you suggest we improve the knowledge mobilization process used during that time?
- Do you have any other suggestions for improving knowledge translation in community-based agencies

Appendix F: Conference Workshop Material

How to implement evidence-based friendship support strategies for adults with intellectual disabilities who have complex needs.

CASEY FULFORD & VIRGINIE COBIGO

APRIL 12, 2018



Presentation Outline

1. Introduction
2. Context of Research Project
3. 5 evidence-based strategies
 - ▶ Description of each strategy
 - ▶ Opinions and recommendations of adults with ID and caregivers
 - ▶ Discussion (4 minutes after each strategy)
4. Recommendations for implementing friendship support strategies
5. General discussion about implementation recommendations (10 minutes)

Importance of Friendships

- ▶ Making friends is a challenge.
- ▶ Individuals with ID want more friends.
- ▶ Physical integration ≠ social inclusion.
- ▶ Staff and family caregivers play a key role!
- ▶ Effective friendship support strategies are needed!

Project Context

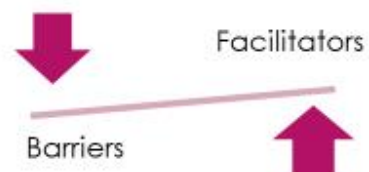
- ▶ What is this project about?
 - ▶ Looking at how to integrate research knowledge with stakeholder perspectives to adapt friendship support strategies.
- ▶ What did we do?
 - ▶ Found strategies to support friendships in research literature
 - ▶ Focus groups to obtain feedback on strategies
- ▶ Now we want your perspectives!

A mother discussing the friendship support her child requires:

“...it's a big chunk of investment and time to develop these friendships, just like our own friendships, right?”

Strategy Implementation Considerations

- ▶ When considering strategies, think about facilitators and barriers to strategy implementation
 - ▶ Organizational constraints
 - ▶ Service-user and caregiver perspectives
 - ▶ Staff perspectives



Strategy Description: Friendship Package

- ▶ Individualized friendship packages:
 - ▶ Personal weekly schedule
 - ▶ Weekly social activity scheduling
 - ▶ Personal information sheet
 - ▶ Friends' contact information
 - ▶ Pictures and information about friends
 - ▶ Activity list
- ▶ Caregivers (staff or family members) would help service-users use the package, as needed.

Friendship Package – Participant Feedback

	Service-users	Caregivers
Pros	Help with planning and organization	Activities scheduled throughout the week
Cons	Wouldn't consistently use schedule Safety concerns & sharing personal information	Skeptical that there are activities to do during weekdays Won't foster true friendships

Discussion Questions

- ▶ Do you think this strategy would be **useful/relevant** for supporting friendships in your work setting?
- ▶ Would it be **feasible** to implement this strategy in your work setting?

Strategy Description: Group Workshops

- ▶ 8-10 weeks of group workshops
- ▶ Focus on helping individuals achieve social goals
- ▶ Weekly home activities
- ▶ Individual support provided (phone/home visit)

Group Workshops – Participant Feedback

	Service-users	Caregivers
Pros	Want to fill up time in their day	Enjoy spending time with a group on a regular basis
	Want to be “closely monitored”	Foster independence Others have social difficulties and social goals
Cons	Some said too big a time commitment	
	Some said too much staff involvement	

Discussion Questions

- ▶ Do you think this strategy would be **useful/relevant** for supporting friendships in your work setting?
- ▶ Would it be **feasible** to implement this strategy in your work setting?

Strategy Description: Best Buddies



- ▶ Service-users would be matched with students from a college/university.
- ▶ For one year partners agree to:
 - ▶ Contacting each other on a weekly basis
 - ▶ One-on-one activity 2-3 times each month
 - ▶ Attending group activities.

Best Buddies – Participant Feedback

	Service-users	Caregivers
Pros	Age of volunteers Consistency and frequency of activities	Age of volunteers Consistency and frequency of activities
Cons		Volunteers might be unreliable

Best Buddies – Participant Feedback

	Service-users	Caregivers
Pros	Age of volunteers	Age of volunteers
	Consistency and frequency of activities	Consistency and frequency of activities
Cons		Volunteers might be unreliable

Strategy Description: Unified Sports

- ▶ Integrated sports teams.
- ▶ Similar skill level.
- ▶ Games would occur on a regular basis.



Unified Sports – Participant Feedback

	Service-users	Caregivers
Pros	Socialize frequently Some really enjoy sports	
Cons	Some do not like sports Integration may be difficult due to differing skill levels	Some do not like sports Community members may not be accepting

Discussion Questions

- ▶ Do you think this strategy would be **useful/relevant** for supporting friendships in your work setting?
- ▶ Would it be **feasible** to implement this strategy in your work setting?

Strategy Description: Community Integration

- ▶ Volunteers paired with individuals with intellectual disabilities.
- ▶ Volunteers introduce service-users to new activities and new people within the community.

Community Integration – Participant Feedback

	Service-users	Caregivers
Pros	Volunteers help guide into the community Support doing activities Helpful when going places for the first time	Volunteers help guide into the community Support doing activities
Cons		

Discussion Questions

- ▶ Do you think this strategy would be **useful/relevant** for supporting friendships in your work setting?
- ▶ Would it be **feasible** to implement this strategy in your work setting?

Key Implementation Suggestions

- ▶ Volunteer commitment and consistency
- ▶ Multiple volunteers per person
- ▶ Guidance through community-based activities
- ▶ Friendship facilitation between individuals
- ▶ Schedule activities at a variety of times throughout the week
- ▶ Provide different options to choose from

Discussion Questions

- ▶ Are these suggestions feasible to implement in your workplace?
- ▶ Is there anything your workplace does that seems contrary to the participants' suggestions?
- ▶ Do you have other suggestions for how to improve friendship support based on your experiences?

Conclusion

- ▶ When choosing strategies to implement it is important to consider:
 - ▶ Service-user and caregiver perspectives
 - ▶ Staff perspectives
 - ▶ Organizational constraints
- ▶ By considering the perspectives of multiple stakeholders, strategies will be more useful, relevant, and feasible.

Appendix G: Links to Online Modules

English module:

https://rise.articulate.com/share/9OZ3LjwsDcdW6nJA16SQZb1Tk_M6QNAO#/?_k=w6h1uy

French module:

<https://rise.articulate.com/share/yEPXMPg-50YbexZsHfPtQaclGE8qDATZ#/>

Appendix H.1: French Online Workshop Slides



Une discussion au sujet du soutien à l'amitié pour les adultes ayant une déficience intellectuelle

CASEY FULFORD & VIRGINIE COBIGO
26 SEPTEMBRE 2018



uOttawa



Aperçu de la présentation

1. Introduction
2. Contexte
3. Discussion sur les stratégies de soutien à l'amitié
4. Recommandations pour la mise en œuvre de stratégies de soutien à l'amitié

Importance de l'amitié

- ▶ Se faire des amis est un défi.
- ▶ Intégration physique ≠ inclusion sociale.
- ▶ Le personnel et les aidants naturels jouent un rôle clé !
- ▶ Les stratégies efficaces de soutien à l'amitié sont nécessaires !



Une mère qui discute du soutien à l'amitié dont son enfant a besoin

"....c'est un gros investissement et du temps pour développer ces amitiés, tout comme nos propres amitiés, n'est-ce pas ?"

Facteurs à prendre en compte lors de l'adaptation des pratiques

Les contraintes de l'agence

- Politiques organisationnelles et valeurs
- Finances
- Temps et ressources

Utilisateurs de services et aidants naturels

- Connaissances, capacités et besoins de soutien
- Réflexions sur la stratégie
- Motivation

Personnel et bénévoles

- Connaissances et compétences
- Réflexions sur la stratégie
- Motivation

Trousses d'amitié

Trousse d'amitié: Description

Des troussees d'amitié individualisées :

- Horaire hebdomadaire personnel
- Horaire hebdomadaire des activités sociales
- Fiche de renseignements personnels
- Coordonnées des amis
- Photos et informations sur les amis
- Liste des activités

Trousse d'amitié: Rétroaction des participants

	Utilisateurs de services	Aidants
Avantages	Planification et organisation	Planification des activités
Désavantages	Utilisation cohérente Préoccupations liées à la sécurité	Sceptiques "Ne favorisera pas de vraies amitiés"

Trousse d'amitié: Rétroaction des participants

	Personnel
Avantages	Rappel au foyer de groupe
	Planification dirigée par la personne
	Mettre l'accent sur le renforcement des compétences
Désavantages	Trouver des activités dans la communauté peut être difficile
	Des liens naturels ?
	Nom de la trousse

Ateliers de groupe

Ateliers de groupe: Description

- ▶ 8 à 10 ateliers de groupe hebdomadaires
- ▶ Se concentrer sur les objectifs sociaux
- ▶ Activités hebdomadaires à domicile
- ▶ Soutien individuel

Ateliers de groupe: Rétroaction des participants

	Utilisateurs de services	Aidants
Avantages	Avoir du temps Vous voulez être "surveillé de près".	Passer beaucoup de temps avec les autres Favoriser l'autonomie Voir les difficultés sociales et les objectifs des autres.
Désavantages	Un engagement trop important Trop d'implication du personnel	

Ateliers de groupe: Rétroaction du personnel

- ▶ **Préoccupations quant à l'utilité de la stratégie :**

- ▶ Transport

- ▶ Stratégie séparée/environnement isolé

Meilleurs amis
(Best buddies)



Meilleurs amis: Description

Jumelage avec des étudiants

Les partenaires sont d'accord de:

- Communiquer les uns avec les autres sur une base hebdomadaire
- Faire des activités ensemble 2 à 3 fois par mois
- Activités de groupe

Meilleurs amis: Rétroaction des participants

	Utilisateurs de service	Aidants
Avantages	Âge des bénévoles	Âge des bénévoles
	Continuité et fréquence	Continuité et fréquence
Désavantages		Les bénévoles pourraient ne pas être fiables.

Meilleurs amis: Rétroaction du personnel

	Personnel
Avantages	Peut être généralisé à l'environnement naturel
Désavantages	S'appuyer sur les bénévoles
Suggestions de mise en œuvre	Mentor dans la communauté Utiliser les intérêts de l'individu Développement des compétences sociales + meilleurs amis → relations naturelles

Sports unifiés
(Unified sports)



Sports unifiés: Description

- ▶ Équipes sportives intégrées
- ▶ Niveau de compétence similaire
- ▶ Jeux se déroulant sur une base régulière



Sports unifiés: Rétroaction des participants

	Utilisateurs de service	Aidants
Avantages	Rencontrer fréquemment d'autres personnes Certains aiment le sport	
Désavantages	Certains n'aiment pas le sport Différents niveaux de compétences	Certains n'aiment pas le sport Acceptation par la communauté?

Sports unifiés: Rétroaction du personnel

Préoccupations au sujet de la faisabilité

- Intensité des ressources
- Manque de continuité

Préoccupations au sujet de l'utilité

- Favorisera-t-il des amitiés ?

Suggestions de mise en œuvre

- Commencer dans l'enfance
- Sports non-compétitifs

Sports unifiés: Rétroaction du personnel

Préoccupations au sujet de la faisabilité

- Intensité des ressources
- Manque de continuité

Préoccupations au sujet de l'utilité

- Favorisera-t-il des amitiés ?

Suggestions de mise en œuvre

- Commencer dans l'enfance
- Sports non-compétitifs

Intégration communautaire: Description



- Jumelé avec des bénévoles
- Introduction à de nouvelles activités et à de nouvelles personnes

Intégration communautaire: Rétroaction des participants

	Utilisateurs de services	Aidants
Avantages	Les bénévoles aident à guider les gens dans la communauté. Soutien pour faire des activités Utile lorsqu'il s'agit de se déplacer pour la première fois	Les bénévoles aident à guider les gens dans la communauté. Soutien pour faire des activités
Désavantages		

Intégration communautaire: Rétroaction du personnel

► Suggestions de mise en œuvre :

- Bénévole comme facilitateur
- Formation des bénévoles
- Orientation spécifique au projet



Conseils
généraux

Suggestions de mise en œuvre - Utilisateurs de services et aidants

Engagement et cohérence des bénévoles

Bénévoles multiples

Orientation par le biais d'activités

Facilitation de l'amitié entre les individus

Programmation d'activités variable

Fournir des options

Suggestions de mise en œuvre - Rétroaction du personnel

Parfois, le soutien du personnel est nécessaire

Engagement en temps des bénévoles

Besoin d'une personnalité et de compétences adéquates

Rôle de bénévole = facilitation de l'amitié

Formation des bénévoles

Suggestions de mise en œuvre - Rétroaction du personnel

Les mesures de soutien devraient varier au fil du temps:

- Objectif : favoriser l'autonomie sociale
- Plus grande implication → se retirer quand c'est possible

• Exemple:



Conclusion

- ▶ Au moment de choisir les stratégies à mettre en œuvre, il est important de tenir compte :
 - ▶ Contraintes organisationnelles
 - ▶ Perspectives des utilisateurs de services et des aidants
 - ▶ Perspectives du personnel
- ▶ Les stratégies seront plus utiles, plus pertinentes et plus réalisables.

Appendix H.2: English Online Workshop Slides



A discussion about friendship support for adults with intellectual disabilities.

CASEY FULFORD & VIRGINIE COBIGO
OCTOBER 24, 2018



Presentation Outline

1. Introduction
2. Strategies to support friendships
3. Recommendations for implementing friendship support strategies

Importance of Friendships

- ▶ Making friends is a challenge.
- ▶ Physical integration ≠ social inclusion.
- ▶ Service providers and family caregivers play a key role!
- ▶ Effective friendship support strategies are needed!



A mother discussing the friendship support her child requires:

“...it's a big chunk of investment and time to develop these friendships, just like our own friendships, right?”

Factors to consider when adapting practices

Constraints of the agency

- Organizational policies and values
- Finances
- Time and resources

Service-users and caregivers

- Knowledge, abilities, and support needs
- Thoughts about the strategy
- Motivation

Service providers

- Knowledge and skills
- Thoughts about the strategy
- Motivation

Strategy 1: Friendship Package

Strategy Description: Friendship Package

Individualized friendship packages:

- Personal weekly schedule
- Weekly social activity scheduling
- Personal information sheet
- Friends' contact information
- Pictures and information about friends
- Activity list

Friendship Package – Participant Feedback

	Service-users	Caregivers
Pros	Planning and organization	Activity scheduling
Cons	Consistent use	Skeptical
	Safety concerns	"Won't foster true friendships"

Friendship Package – Service Provider Feedback

	Service Providers
Pros	Reminder in group home
	Person directed planning
	Focus on skill building
Cons	Finding activities in the community can be difficult
	Natural connections?
	Package name

Strategy 2: Group Workshops

Strategy Description: Group Workshops

- ▶ 8-10 weeks of group workshops
- ▶ Focus on helping individuals achieve social goals
- ▶ Weekly home activities
- ▶ Individual support provided (phone/home visit)

Group Workshops – Participant Feedback

	Service-users	Caregivers
Pros	Have time	Spending frequent time with others
	Want to be “closely monitored”	Foster independence
		See others' social difficulties and goals
Cons	Too big a commitment	
	Too much service-provider involvement	

Group Workshops – Service Provider Feedback

- ▶ **Concerns about utility of strategy:**

- ▶ Transportation
- ▶ Segregated strategy/isolated environment

Strategy 3:
Best Buddies



Strategy Description: Best Buddies

Service-users matched with students.

Partners agree to:

- Contacting each other on a weekly basis
- One-on-one activity 2-3 times each month
- Group activities.

Best Buddies – Participant Feedback

	Service-users	Caregivers
Pros	Age of volunteers	Age of volunteers
	Consistency and frequency	Consistency and frequency
Cons		Volunteers might be unreliable

Best Buddies – Service Provider Feedback

	Service Providers
Pros	Can generalize to natural environment
Cons	Relying on volunteers
Implementation suggestions	Mentor in community Use individual's interests Social skills building + best buddies → natural relationships

Strategy 4:
Unified Sports



Strategy Description: Unified Sports

- ▶ Integrated sports teams.
- ▶ Similar skill level.
- ▶ Games occurring on regular basis.



Unified Sports – Participant Feedback

	Service-users	Caregivers
Pros	Socialize frequently Some enjoy sports	
Cons	Some dislike sports Differing skill levels	Some dislike sports Community acceptance

Unified Sports – Service Provider Feedback

Concerns about feasibility

- Resource intensive
- Lack of consistency

Concerns about utility

- Will it foster friendships?

Implementation suggestions

- Begin in childhood
- Non-competitive sports

Strategy 5: Community Integration

Strategy Description: Community Integration



- ▶ Paired with volunteers
- ▶ Introduction to new activities and new people

Community Integration – Participant Feedback

	Service-users	Caregivers
Pros	Volunteers help guide into the community Support doing activities Helpful when going places for the first time	Volunteers help guide into the community Support doing activities
Cons		

Community Integration – Participant Feedback

	Service-users	Caregivers
Pros	Volunteers help guide into the community Support doing activities Helpful when going places for the first time	Volunteers help guide into the community Support doing activities
Cons		

Implementation Suggestions – Service-users & Caregivers

**Volunteer
commitment and
consistency**

Multiple volunteers

**Guidance through
activities**

**Friendship
facilitation between
individuals**

**Variable activity
scheduling**

Provide options

Implementation Suggestions – Service Provider Feedback



Implementation Suggestions – Service Provider Feedback

Supports should vary over time:

- Goal: foster social independence
- Higher involvement → pull back when possible

• Example:





Conclusion

- ▶ When choosing strategies to implement it is important to consider:
 - ▶ Organizational constraints
 - ▶ Service-user and caregiver perspectives
 - ▶ Service-provider perspectives
- ▶ Strategies will be more useful, relevant, and feasible

Appendix I.1 : French Website Questionnaire

Renseignements généraux :

1. **Quels sont les trois premiers caractères du code postal de votre organisme de services?** _____
2. **Quel âge avez-vous?** _____
3. **Quel est votre fonction ou votre rôle quant au soutien aux adultes ayant une déficience intellectuelle?**

☐ Directeur(trice) / Gestionnaire – Préciser la fonction ou le rôle :

☐ Personnel offrant un soutien direct – Préciser la fonction ou le rôle :

☐ Bénévole – Préciser la fonction ou le rôle :

☐ Autre – Préciser la fonction ou le rôle :

Depuis combien d'années travaillez-vous dans le domaine du soutien aux personnes ayant une déficience intellectuelle? _____

4. **Est-ce que vous savez lu le contenu sur le site Internet?**

☐ Oui – j'ai lu tout le contenu (passer à la question 6)

☐ Partiellement - j'ai lu une partie du contenu sur le site Internet

Sections lues :

☐ Non – je n'ai pas lu le contenu sur le site Internet (fin du questionnaire)

5. **Veuillez expliquer pourquoi vous n'avez pas lu tout le contenu sur le site Internet.**

Utilité de l'information:

- 6. Il serait possible d'utiliser le contenu sur le site Internet pour adapter les pratiques visant à favoriser les amitiés chez les adultes ayant une déficience intellectuelle.**

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Comment serait-il possible d'utiliser le contenu pour aider votre organisme à adapter ses pratiques?

Pourquoi le contenu pourrait-il ne pas être utile pour aider à adapter les pratiques?

- 7. Le site Internet vous a apporté de l'information nouvelle sur les stratégies pour favoriser les amitiés chez les adultes ayant une déficience intellectuelle.**

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Quelle information nouvelle a-t-il apportée?

8. En quoi les stratégies présentées sur le site Internet concordent-elles ou contrastent-elles avec les valeurs et objectifs de votre organisation en ce qui a trait au soutien social offert aux adultes ayant une déficience intellectuelle?

Clarté :

9. Le site Internet était clair et facile à comprendre.

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Comment serait-il possible d'améliorer l'Aperçu de l'information à cet égard?

Suggestions pour améliorer le contenu :

10. Quelle information additionnelle aurait-il fallu inclure sur le site Internet pour en faire un outil plus utile pour adapter les pratiques favorisant les amitiés chez les adultes ayant une déficience intellectuelle?

11. Quelle information n'était-il pas nécessaire d'inclure sur le site Internet?

Diffusion de l'information :

12. Quelle serait la meilleure méthode pour diffuser l'information incluse sur le site Internet?

- ☐ Présentation en personne
- ☐ Présentation en ligne / webinaire
- ☐ Document envoyé en ligne
- ☐ Site Internet
- ☐ Autre – Préciser : _____

13. En quoi la ou les méthodes de diffusion que vous avez choisies facilitent-elles l'utilisation de l'information pour les organismes de services qui offrent un soutien aux adultes ayant une déficience intellectuelle?

Commentaires additionnels :

14. Veuillez nous faire part de tout commentaire additionnel que vous pourriez avoir au sujet du contenu ou du format sur le site Internet.

Futurs sujets de recherche :

15. Veuillez nous faire part de toute suggestion de futur sujet de recherche lié à l'utilisation de l'information probante issue de la recherche pour modifier les pratiques dans les milieux communautaires.

16. Veuillez nous faire part de toute suggestion de futur sujet de recherche lié au soutien aux amitiés chez les personnes ayant une déficience intellectuelle.

MERCI POUR VOTRE PARTICIPATION!

*****VEUILLEZ REMPLIR LA PAGE SUIVANTE S'IL VOUS INTÉRESSE DE PARTICIPER À UNE ENTREVUE TÉLÉPHONIQUE DE SUIVI *****

Participation à une future activité de recherche

17. Nous tiendrons des entrevues téléphoniques de suivi au sujet des réponses au présent questionnaire. Celles-ci nous aideront à mieux comprendre comment rendre les résultats de recherche plus pertinents et accessibles pour les organismes communautaires.

Êtes-vous intéressé(e) à participer à une entrevue téléphonique de suivi?

☐ Oui

☐ Non

Si cela vous intéresse, veuillez indiquer vos coordonnées ci-après. Il est possible que nous vous contactions pour une entrevue téléphonique de suivi. Si vous fournissez vos coordonnées, vos réponses au présent questionnaire ne seront pas anonymes, car nous pourrions vous poser des questions liées directement aux réponses que vous avez fournies.

Nom au complet : _____

Adresse de courriel : _____

Numéro de téléphone : _____

Meilleur moment de la journée pour vous appeler : _____

Appendix I.2 French Workshop Questionnaire

Renseignements généraux :

1. **Quels sont les trois premiers caractères du code postal de votre organisme de services?** _____
2. **Quel âge avez-vous?** _____
3. **Quel est votre fonction ou votre rôle quant au soutien aux adultes ayant une déficience intellectuelle?**

☐ Directeur(trice) / Gestionnaire – Préciser la fonction ou le rôle :

☐ Personnel offrant un soutien direct – Préciser la fonction ou le rôle :

☐ Bénévole – Préciser la fonction ou le rôle :

☐ Autre – Préciser la fonction ou le rôle :

Depuis combien d'années travaillez-vous dans le domaine du soutien aux personnes ayant une déficience intellectuelle? _____

Utilité de l'information:

4. **Il serait possible d'utiliser le contenu de la présentation pour adapter les pratiques visant à favoriser les amitiés chez les adultes ayant une déficience intellectuelle.**

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Comment serait-il possible d'utiliser le contenu pour aider votre organisme à adapter ses pratiques?

Pourquoi le contenu pourrait-il ne pas être utile pour aider à adapter les pratiques?

- 5. La présentation vous a apporté de l'information nouvelle sur les stratégies pour favoriser les amitiés chez les adultes ayant une déficience intellectuelle.**

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Quelle information nouvelle a-t-il apportée?

- 6. En quoi les stratégies présentées dans la présentation concordent-elles ou contrastent-elles avec les valeurs et objectifs de votre organisation en ce qui a trait au soutien social offert aux adultes ayant une déficience intellectuelle?**

Clarté :

- 7. La présentation était clair et facile à comprendre.**

Fortement en désaccord	Légèrement en désaccord	Neutre	Légèrement d'accord	Fortement d'accord
1	2	3	4	5

Comment serait-il possible d'améliorer l'Aperçu de l'information à cet égard?

Suggestions pour améliorer le contenu :

8. **Quelle information additionnelle aurait-il fallu inclure dans la présentation pour en faire un outil plus utile pour adapter les pratiques favorisant les amitiés chez les adultes ayant une déficience intellectuelle?**

9. **Quelle information faudrait-il retirer de l'Aperçu de l'information probante?
Quelle information n'était-il pas nécessaire d'inclure?**

Diffusion de l'information :

10. **Quelle serait la meilleure méthode pour diffuser l'information incluse dans l'Aperçu de l'information probante?**

- ☐ Présentation en personne
- ☐ Présentation en ligne / webinaire
- ☐ Document envoyé en ligne
- ☐ Autre – Préciser : _____

11. **En quoi la ou les méthodes de diffusion que vous avez choisies facilitent-elles l'utilisation de l'information pour les organismes de services qui offrent un soutien aux adultes ayant une déficience intellectuelle?**

Commentaires additionnels :

12. Veuillez nous faire part de tout commentaire additionnel que vous pourriez avoir au sujet du contenu ou du format de l'Aperçu de l'information probante.

Futurs sujets de recherche :

13. Veuillez nous faire part de toute suggestion de futur sujet de recherche lié à l'utilisation de l'information probante issue de la recherche pour modifier les pratiques dans les milieux communautaires.

14. Veuillez nous faire part de toute suggestion de futur sujet de recherche lié au soutien aux amitiés chez les personnes ayant une déficience intellectuelle.

MERCI POUR VOTRE PARTICIPATION!

*****VEUILLEZ REMPLIR LA PAGE SUIVANTE S'IL VOUS INTÉRESSE DE PARTICIPER À UNE ENTREVUE TÉLÉPHONIQUE DE SUIVI *****

Participation à une future activité de recherche

15. Nous tiendrons des entrevues téléphoniques de suivi au sujet des réponses au présent questionnaire. Celles-ci nous aideront à mieux comprendre comment rendre les résultats de recherche plus pertinents et accessibles pour les organismes communautaires.

Êtes-vous intéressé(e) à participer à une entrevue téléphonique de suivi?

☐ Oui

☐ Non

Si cela vous intéresse, veuillez indiquer vos coordonnées ci-après. Il est possible que nous vous contactions pour une entrevue téléphonique de suivi. Si vous fournissez vos coordonnées, vos réponses au présent questionnaire ne seront pas anonymes, car nous pourrions vous poser des questions liées directement aux réponses que vous avez fournies.

Nom au complet : _____

Adresse de courriel : _____

Numéro de téléphone : _____

Meilleur moment de la journée pour vous appeler : _____

Appendix I.3: English Website Questionnaire

Background Information:

1. What are the first three digits of the postal code of your service agency?

2. How old are you? _____

3. What is your position/role in relation to supporting adults with intellectual disabilities?

☐ Director/Manager – Specify
position/role: _____

☐ Direct support staff – Specify
position/role: _____

☐ Volunteer – Specify
position/role: _____

☐ Other – Specify
position/role: _____

How many years have you been working in the area of supporting individuals with intellectual disabilities? _____

4. Did you read the content on the website?

☐ Yes - Read all the content (skip to question 6)

☐ Partly - Read part of the content on the website

Sections read:

☐ No - Did not read any of the content on the website (terminate questionnaire)

5. Please explain why you did not read all the content on the website.

Utility of Information:

6. The content included on the website could be used to adapt practices for supporting friendships for adults with intellectual disabilities.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

How could the content be used to help your organization change practices?

Why wouldn't the content be useful to help change practices?

7. The website provided you with new information on strategies for supporting friendships for adults with intellectual disabilities.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

What new information did it provide?

8. How do the strategies presented on the website align with or differ from the values and goals of your organization, with regard to providing social support for adults with intellectual disabilities?

Clarity:

9. The website was clear and easy to understand.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

How could the website be improved in this regard?

Suggestions for Improving Content:

10. What additional information should have been included on the website to make it a more useful tool for adapting practices to support friendships for adults with intellectual disabilities?

11. What information was not necessary to include on the website?

Distribution of Information:

12. What would be the most useful method of distributing the information included on the website?

- ☐ In-person presentation
- ☐ Online presentation/webinar
- ☐ Document sent online
- ☐ Website
- ☐ Other – Specify: _____

13. How would the distribution method(s) you selected facilitate use of the information for service agencies that support adults with intellectual disabilities?

Additional Comments:

14. Please provide any additional comments you have about the content or format of the website.

Future Research Topics:

15. Please provide suggestions for future research topics related to using research evidence to change practices in community-based settings.

- 16. Please provide suggestions for future research topics related to supporting friendships for individuals with intellectual disabilities.**

THANK YOU FOR YOUR PARTICIPATION!

*****PLEASE COMPLETE THE FOLLOWING PAGE IF YOU ARE INTERESTED IN PARTICIPATING IN A FOLLOW-UP PHONE INTERVIEW*****

Future Research Participation:

- 17. We will be conducting follow-up phone interviews about responses to this questionnaire. This will help us gain a more comprehensive understanding about how to make research findings more relevant and accessible to community-based agencies.**

Are you interested in participating in a follow-up phone interview?

☐ Yes

☐ No

If yes, please provide your contact information below. We may contact you for a follow-up phone interview. If you provide your contact information, your responses to this questionnaire will not be anonymous, as we may ask you follow-up questions specific to the responses you provided.

Full Name: _____

Email Address: _____

Phone Number: _____

Best time of day to reach you: _____

Appendix I.4: English Workshop Questionnaire

Background Information:

1. What are the first three digits of the postal code of your service agency?

2. How old are you? _____

3. What is your position/role in relation to supporting adults with intellectual disabilities?

☐ Director/Manager – Specify position/role: _____

☐ Direct support staff – Specify position/role: _____

☐ Volunteer – Specify position/role: _____

☐ Other – Specify position/role: _____

How many years have you been working in the area of supporting individuals with intellectual disabilities? _____

4. Did you read the Presentation?

☐ Yes - Read the Presentation in full (skip to question 6)

☐ Partly - Read part of the Presentation

Sections read:

☐ No - Did not read the Presentation (terminate questionnaire)

5. Please explain why you did not read the full Presentation.

Utility of Information:

6. The content included in the Presentation could be used to adapt practices for supporting friendships for adults with intellectual disabilities.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

How could the content be used to help your organization change practices?

Why wouldn't the content be useful to help change practices?

7. The Presentation provided you with new information on strategies for supporting friendships for adults with intellectual disabilities.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

What new information did it provide?

8. How do the strategies presented in the Presentation align with or differ from the values and goals of your organization, with regard to providing social support for adults with intellectual disabilities?

Clarity:

9. The Presentation was clear and easy to understand.

Strongly Disagree	Slightly Disagree	Neutral	Slightly Agree	Strongly Agree
1	2	3	4	5

How could the Presentation be improved in this regard?

Suggestions for Improving Content:

10. What additional information should have been included in the Presentation to make it a more useful tool for adapting practices to support friendships for adults with intellectual disabilities?

11. What information should be removed from the Presentation? What information was not necessary to include?

Distribution of Information:

12. What would be the most useful method of distributing the information included in the Presentation?

- ☐ In-person presentation
- ☐ Online presentation/webinar
- ☐ Document sent online
- ☐ Website
- ☐ Other – Specify: _____

13. How would the distribution method(s) you selected facilitate use of the information for service agencies that support adults with intellectual disabilities?

Additional Comments:

14. Please provide any additional comments you have about the content or format of the Presentation.

Future Research Topics:

15. Please provide suggestions for future research topics related to using research evidence to change practices in community-based settings.

- 16. Please provide suggestions for future research topics related to supporting friendships for individuals with intellectual disabilities.**

THANK YOU FOR YOUR PARTICIPATION!

*****PLEASE COMPLETE THE FOLLOWING PAGE IF YOU ARE INTERESTED IN PARTICIPATING IN A FOLLOW-UP PHONE INTERVIEW*****

Future Research Participation:

- 17. We will be conducting follow-up phone interviews about responses to this questionnaire. This will help us gain a more comprehensive understanding about how to make research findings more relevant and accessible to community-based agencies.**

Are you interested in participating in a follow-up phone interview?

☐ Yes

☐ No

If yes, please provide your contact information below. We may contact you for a follow-up phone interview. If you provide your contact information, your responses to this questionnaire will not be anonymous, as we may ask you follow-up questions specific to the responses you provided.

Full Name: _____

Email Address: _____

Phone Number: _____

Best time of day to reach you: _____

Appendix J: Interview Protocol with Service-Providers

Details:

- Duration: ½ hour
- Location: phone interview

Overview:

- *Important consent form information:*
 - Reiterate that the project is voluntary.
 - Remind the participant that the interview is audio-recorded.
- *Research objective:*
 - We aim to understand how service-providers and clinicians can use available research knowledge about supporting friendships for adults with intellectual disabilities.
- *Purpose/Context*
 - We will ask follow-up questions to the questionnaire you completed about the website on supporting friendships of adults with intellectual disabilities.
 - Your feedback will provide valuable information on how to make research findings more relevant and accessible to service-providers.
- *Questions*
 - Obtaining clarification about questionnaire responses:
 - *We will remind participants about the content of the website*
 - *We will remind participants about the questions from the questionnaire they completed and reiterate their previous answers for which we are seeking clarification.*
 - *We will ask relevant follow-up questions (e.g., Can you provide more clarification regarding X? Why would X be helpful? How would you use X to change practices? Why wasn't X accessible? Do you have any suggestions for how to do X?).*
 - Factors influencing perceptions of the content
 - What factors do you think would have the biggest impact on how the content of the website was viewed/used by service-providers?
 - Would this be affected by staff position, size of organization, service-user characteristics?
 - Do you think there would be differences in how the content was perceived/used based on the mandate/vision of an organization?
 - How so? / Why not?
 - Can you provide an example (in relation to your organization)?
 - Is there anything else you would like to discuss that has not yet been covered in the interview?