Protection of Privacy of Information Rights among Young Adults with Developmental Disabilities

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Abstract Protection of privacy of information for young adults with developmental disabilities and their families is essential to promote quality of life, well-being, empowerment, and inclusion. Despite this, the young adults’ information privacy rights are increasingly at risk. This paper provides a scoping review, applying Arksey and O’Malley’s (2005) approach, of all published peer-reviewed journal articles and gray literature to examine the barriers and facilitators in utilization of legislation that protects the collection, use, disclosure, and access of personal information in Canada. The scoping review process was further expanded with a rigorous reliability method and applied a socio-ecological framework to the final 47 studies. National and international policy and legislation (macro level), organization-based factors (meso), young adults and community interactions (exo), and individual disability related factors (micro) are examined. The review identifies the barriers and highlights the importance of facilitators for acting on personal privacy rights.

Keywords Information privacy rights · Canada · PIPEDA · PHIPA · Confidentiality · Personal information protection

Young adults with developmental disabilities (YADD) and their families are at risk of exploitation in terms of privacy and protection of their personal information (Joffe, 2010). Their increasing dependency on multiple community-based and private agencies creates a scenario where a wide range of personal information is retained and shared through the course of servicing these individuals and their families over time. YADD are vulnerable not only

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because they are in a sensitive period transitioning into adulthood but also as they have complex developmental needs and may experience difficulties making their own decisions (Dyke et al., 2016). They may also have concurrent health and mental health needs which require support, and even as adults may frequently depend on secondary decision makers to protect their privacy of information rights (Geist, 2016).

Developmental disabilities (DDs), which include intellectual disability, autism, down syndrome, fragile x syndrome, cerebral palsy, and developmental delays, are lifelong and affect multiple aspects of psychosocial development, physical functioning, and participation in daily activities (Developmental Services Ontario (DSO), 2016; Roebuck et al., 2008). Individuals with DDs may have deficits in their cognitive, decision-making, comprehension, and communication capacity (Roebuck et al., 2008) that increases their exposure to human rights violations related to privacy of information (Fogden et al., 2016). They or their family caregivers and service providers often do not have the necessary resources to defend their privacy rights to personal information.

While legislation in Canada is well developed and in place to guide the protection of personal information (e.g., Personal Information Protection and Electronic Documents Act (PIPEDA), 2000), and health information for individuals (e.g., Personal Health Information Protection Act (PHIPA), 2004), the translation of relevant legislation as required for individuals at-risk of understanding or communicating their rights is not. This impression is informed by our findings from our recent and on-going research studies on families of children and young adults with developmental disabilities (Khanlou et al., 2017a; Khanlou et al., 2017c; Khanlou, 2018). During the data collection phase of these projects, family caregivers, service providers, and YADD frequently reported concerns they faced with the collection and use of their personal information. Specifically, they relayed concerns about the extensive paper work, dispersed services, navigation across multiple service sectors with repetition of requests for personal information, financial difficulties, social isolation, and stigma. Immigrant family caregivers of YADD faced additional information privacy concerns specific to language fluency, lack of social networks, and new knowledge required post-migration of service delivery systems and their rights, which were reported to affect their access to and utilization of health and social services (Khanlou et al., 2017a; Khanlou et al., 2017b; Khanlou et al., 2017c; Khanlou, 2018). Their concerns and these factors influence the privacy rights of YADD in a challenging manner: Many YADD and their parents continue to remain uncertain as to who is accountable for the protection of their privacy rights given the complexity and persistence of developmental challenges of the young adults.

In Ontario, Canada, persons with DDs are permitted to remain in their secondary school until they reach 21 years of age. Thus, even though they are adults as of 18 years of age, their privacy and confidentiality rights are largely protected by the adherence to privacy laws within their school environment. However, following completion of school, the young adults with developmental disabilities can take different pathways ranging from partial employment, volunteer work, vocational training, day programs, or to no involvement in activities outside the home. Once these young adults leave the protection of their school settings, they are increasingly dependent on both private and public agencies from within both the social and health sectors. This dependency on multiple organizations to provide needed services, supervision, care, employment, or education—commercially based or not—increases dramatically as the young adults transition into adulthood.

Given the significant gap between application of relevant legislation or information privacy evidence and the needs of young adults with developmental disabilities, the
YADD Privacy Project was developed (Khanlou, et al., 2017b). As part of the project, a methodologically rigorous scoping review was conducted to address this gap by synthesizing evidence on information privacy rights for YADD in Canada. The goals of this comprehensive scoping review of both published peer-reviewed articles and online gray literature were to: (1) examine the range, depth and nature of both the scholarly and gray literature related to access to privacy of information rights and utilization of legislation in Canada for the provision of services to young adults with developmental disabilities (PIPEDA, 2000 or PHIPA, 2004), (2) apply a socio-ecological framework (Bronfenbrenner & Ceci, 1994) to the findings to illustrate the barriers and facilitators of information privacy rights for young adults with developmental disabilities, and (3) to contribute to the development of future strategies and solutions enhancing information privacy rights with evidence-based recommendations.

Methods

Our protocol was developed using the scoping review methodology proposed by Arksey and O’Malley (2005), which has a five-step process for conducting scoping reviews. This method entails (1) identification of the research question, (2) identification of relevant studies, (3) study selection, (4) charting the data, and (5) synthesizing and reporting of the results. In addition, we refined the scoping review process to increase methodological rigor, by including three more components as suggested by Tricco et al. (2016) and Colquhoun et al. (2014) and their colleagues, including establishing a protocol, utilizing at least two reviewers and calculation of reliability, a reporting checklist, and conducting a consultation exercise to ensure our results are useful to advancing the field.

Step 1 We identified the research question as follows, “What does the scholarly and grey literature on information privacy in relation to PIPEDA or PHIPA inform us about the barriers and facilitators young adults with developmental disabilities encounter when accessing and utilizing their privacy rights?”

Step 2 Next, relevant peer-reviewed studies were identified by searching electronic databases: ProQuest, JSTOR, Scholars Portal, EBSCO, Web of Science, PubMed, PsychINFO, Scopus, and CANLII (for legal cases and briefs), using specific search terms: PIPEDA OR PHIPA OR information privacy AND developmental disabilities AND Canada. The gray literature search was conducted using the Google search engine, and keywords/phrases were either (a) barriers to PIPEDA for young adults with developmental disabilities in Canada or (b) barriers to PHIPA for young adults with developmental disabilities in Canada. The database searches were not limited by language or type of publication, but location for keywords was restricted to Canada. Specifically, we searched Google Search and websites of agencies that service YADD. The electronic searches retrieved 9299 articles (Fig. 1), and 25 articles through hand searching. Ten duplicates were removed. Search and keyword strategy were developed by research team members and approved by the study Principle Investigator and the health sciences librarian.

Step 3 Abstracts of identified articles were reviewed to assess if they met the inclusion and exclusion criteria. Articles were eligible if they were written in a
peer-reviewed journal or published online, including policy documents, websites, and commentary, between January of 2000 and November of 2017. All titles and abstracts were individually examined by the reviewers AM and AK. We excluded any articles or gray literature that was aimed at the general population or cited the legislation without detailed explanation or information on application in servicing YADD. Articles not pertaining to access to or utilization of privacy legislation were excluded. Abstracts were included if they described issues related to PIPEDA or PHIPA and legislation with young adults with developmental disabilities. We included articles based on other populations (e.g. physical disability, and mental illness) and countries (EU and USA) only if their findings were also relevant to
the developmental disability community. Articles discussing children and youth under the age of 16 were not included, and studies of adults were only included if a large portion of the reported sample in the study included young adults under 28 years of age. To ensure comprehensiveness in the evidence base, we also supplemented our list of included articles with academic literature that discussed information privacy with similarly vulnerable populations (e.g., those with mental health or decision-making capacity issues). We included studies conducted outside of Canada when findings were informative for barriers and facilitators of privacy legislation. Forty-seven articles (24 peer-reviewed and 23 gray literature) fulfilled the eligibility criteria for the scoping review.

Step 4 Information was captured on Excel 2011. To ensure reliability between reviewers, a series of training exercises were conducted and inter-rater agreement for both the study inclusion and data charting phases. Changes were made based on feedback until there was consensus regarding the face validity of the tool by the two reviewers. A total of 10 randomly selected articles were evaluated by two reviewers, and 5 by three reviewers, to assess the level of agreement across all categories for each article. Reliability for level of agreement on items on the abstraction form ranged from 61 to 96%. Given the high degree of variability among the published and gray literature, the mean level of agreement obtained (79.5%) was deemed to be sufficient. All changes were verified by reviewers to ensure data accuracy.

Results

All analyzed articles described legislation focused on information privacy rights, in relation to collection, use, disclosure or sharing and correction, or access for checking. Eighty percent of the articles (peer-reviewed published and gray literature) also addressed confidentiality and/or autonomy while only 6 articles (12%) reviewed ethical issues related to accountability on the part of the service organization. Full-length manuscripts, case studies, legislative acts, policy reports, professional practice guidelines, service provider resources as well as literature and policy reviews were obtained for all abstracts identified for inclusion by both reviewers.

Location

Fifty-one percent of the 47 articles included for full text review and synthesis represented peer-reviewed published articles and 48% represented documents selected through the gray literature search. Of the published articles, five were based in the USA and three in the EU.

Population

While 39 articles were related to young adults with developmental disability, 8 articles from the published and gray literature did not discuss young adults or developmental disability, but to consumers of technology \( (n = 4) \), genetic researchers \( (n = 1) \), and patients with mental health diagnoses \( (n = 3) \).
Legal and Ethical Themes

Within the whole sample (n = 47), all articles discussed relevant legal and ethical issues but through a variety of sub-themes. Fifty-five percent of articles discussed collection of personal information, while 42 to 45% focused on use disclosure of personal information and 25% discussed the legal and ethical issues related to correction or access to personal information that is kept within the organization. With respect to ethical principles related to the privacy of information rights, 83% focused on confidentiality, 38% on the need for autonomy, and 13% discussed accountability on the part of the organization collecting the personal information.

Types of Articles

Articles from both the peer-reviewed published and gray literature included a variety of formats, from commentary to policy/legislation and literature reviews to empirical studies utilizing qualitative and/or quantitative data, and professional or organization-based guidelines. Policy and legislation reviews or discussions accounted for 22% of the total articles, while 17% represented the empirical research studies and 32% were based on reviews of the literature (please see Table 1). Fifty-six percent of articles representing the gray literature were published as guidelines, either to be used as a general resource to consumers of the organization (n = 15), or to support health professional practice (n = 5), or to communicate the organization’s policy and procedures (n = 6). Of the five articles published as professional practice guidelines specifically addressing privacy rights for use by health professionals (e.g., Occupational Therapists, Speech/Language Pathologists, Personal Support Workers), none discussed relevant parts of the legislation, or potential strategies to help the professional protect information privacy rights of those they are supporting. Rather, they referred the reader to read the PIPEDA. The remaining 46% of published gray literature included websites, information sheets, press releases, reports to the Canadian parliament, dissertation, relevant legislation, and a document of meeting minutes (please see Table 2).

Discussion

Despite legislation that provides standards on how to collect, use, and disseminate personal information to protect privacy, this review identifies specific factors as barriers and facilitators to access and use of information privacy rights for YADD and their families. These findings were classified according to Bronfenbrenner’s socio-ecological framework (Bronfenbrenner & Ceci, 1994) of classifying macro level (policy, legislation, attitudes), meso level (organization), exo level (community interactions), and micro level (individual, family), to more fully understand influences on access and utilization of privacy rights for young adults with developmental disabilities (please see Fig. 2).

Macro Level: Policy and Legislation (National and International)

At the macro level, this review suggests that aspects of policy and legislation, both in Canada and internationally, are identified as barriers to YADD exercising their privacy rights. The main factors shown to act as barriers can be categorized as relating to presentation of policy, gaps in legislation, and rise of corporate interests. Poorly written policy that is unclear (Dyke,
| Author                        | Type of study                  | Participants                  | Country and law                  | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified                                                                 |
|-------------------------------|--------------------------------|-------------------------------|----------------------------------|---------------------|--------------------------|---------------------------|--------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| 1. Mills et al., 2003         | Policy analysis                | Not applicable                | Canada: PIPEDA, PHIPA            | Health information  | Collection Disclosure    | Not addressed             | 1. Lack of shared databases 2. Poor integration of policy and technology 3. Lack of agreement on keeping privacy and security of PHI 4. Lack of commitment to technological networks | 1. Increasing use of “anonymising” data through encryption 2. Advocating for patient privacy 3. Establishing strong policies 4. Willingness to invest in technological advances |
| 2. Lafky & Horan, 2011        | Mixed methods: qualitative interviews and quantitative survey | PHR users: unwell, disabled and well adults | USA                             | Personal health information | Use Access Confidentiality (breach) Autonomy | Not addressed | 1. Low levels of experience with managing PHI 2. Disabled less concerned, and less in control with privacy 3. Lower engagement in privacy-protecting activities 4. Underrepresentation of disabled people 5. Records which may be scattered among multiple providers | 1. Heightened access and sense/perception of control for those that are more concerned with privacy and more able to protect their health records privacy |
| 3. Dyke, et al., 2016         | Comparative legal and policy analysis | None (qualified researchers) | Canada PIPEDA                   | Health information  | Disclosure Confidentiality | 1. Not complying with PIPEDA legislative requirements 2. Difficulties identifying jurisdiction 3. Complicated legal framework for privacy law (public and private; federal and provincial) | 1. Understanding local norms and standards and legal requirements 2. Understanding factors influencing consumer adoption of health information management tools 3. Using an accountability model for ensuring that |
| Author                  | Type of study                          | Participants                      | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                                       | Facilitators identified                                                                 |
|-------------------------|----------------------------------------|-----------------------------------|-----------------|---------------------|-------------------------|---------------------------|--------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------|
| Yalon-Chanimiz, 2009    | Review of literature and a conceptual model | Adults with intellectual disability | USA             | Personal health information | Collection access       | Autonomy                  | 4. Effort and cost of sharing, protecting, and ability to publishing                                     | Canadian privacy standards are in place                                                |
| Urowitz et al., 2008    | QUAN (National Scan)-survey - prospective, cross-sectional | CEOs of hospitals \(N=83\) | Canada          | Electronic health records | Use and access           | Confidentiality          | 1. Absence of technology to facilitate the electronic health record                                      | 1. Use of electronic patient portals                                                                                   |
|                         |                                        |                                   | PHIPA           |                                    |                         |                           | 2. Financial resources                                                                                   | 2. Cultural shift of healthcare providers: to give up “ownership” of the files              |
|                         |                                        |                                   |                 |                                    |                         |                           | 3. Patient computer literacy                                                                              |                                                                                           |
|                         |                                        |                                   |                 |                                    |                         |                           | 4. Lack of hospital survey on patient needs for HER                                                        |                                                                                           |
|                         |                                        |                                   |                 |                                    |                         |                           | 5. Unwillingness of hospitals to providing                                                                |                                                                                           |
| Author | Type of study | Participants | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified | Facilitators identified |
|--------|---------------|--------------|-----------------|---------------------|--------------------------|---------------------------|---------------------|------------------------|
| 6. Siegel, et al., 2009 | Comparative legal and policy analysis | Consumers of technology | Canada PIPEDA USA, EU | Personal information | Use (security breach) | Accountability | patients with access to their EHR | 1. Exploding growth of social media, yet lacks detail how information is used for advertising, and how to verify consent from non-users 2. Regulations are “piece-meal” not explained enough 3. Developments in Canada have been only advisory | 1. Jurisdiction over foreign organizations 2. Clear, consistent communication as to the use of the information across platforms |
| 7. Geist, 2016 | Critical review of legislature | Consumers of technology | Canada PIPEDA | Personal information | Disclosure (security breach) | Confidentiality accountability | 1. Corporate, lobby group focus on commercial concerns 2. Absence of “order-making power” 3. Lack of penalties for privacy violations 4. Weak protections when outsourcing information to low protection jurisdictions | 1. Public engagement, protests for privacy rights 2. Mandatory breach disclosure requirements |
| 8. Larivie’re-Bastien, & Racine, 2011 | Review | Adolescents with cerebral palsy | USA | Health information | Collection | Confidentiality autonomy | 1. Failure to adjust and focus on disability prevents focus on traditional adolescence issues 2. Lack of preparation to the transition and social isolation | 1. Positive attitudes and trustful, open provider-patient relationships free of stereotypes 2. Technology for communication, time and resources help with autonomous consent |
| Author           | Type of study | Participants | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified                                                                 |
|------------------|---------------|--------------|-----------------|--------------------|------------------------|---------------------------|-------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| 9. Austin, 2006  | Review: case and legislature | Not applicable | None identified | Consumer information | Collection use          | Confidentiality autonomy   | 3. Difficulty obtaining health information 4. Needs for confidentiality and privacy are not respected and not acknowledged 5. Issues of informed consent and capacity often not addressed: opportunity to take part in decision-making not provided enough | 3. Healthcare providers can facilitate implicit personal autonomy even if it contradicts professional opinions |
| 10. Repetto, et al., 2008 | Review | 1. YADD in transition: from Grade 6 to 12 students 2. Family caregiver 3. Teachers | USA HIPPA FERPA | Personal information | Collection use disclosure Access | Confidentiality Autonomy | 1. Legislature limited to record keeping and documentation and may not cover the broader needs 2. Young adults with DD do not have the knowledge, skills and are not health literate | 1. Improved guidelines for teachers to support confidentiality within the classroom 2. Teaching students how to balance the advantages and disadvantages of releasing personal health information 3. Empowering and preparing students to make informed decisions |
| Author                  | Type of study | Participants | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified |
|-------------------------|---------------|--------------|-----------------|---------------------|--------------------------|-----------------------------|-------------------------------------------------------------------------------------|--------------------------|
| Chan, & O’Brien, 2011   | Review        | Not applicable | Canada          | PHIPA               | Health information       | Confidentiality, Autonomy   | 3. Standards, curriculum materials and legislation do not refer to disabilities   | choices related to disclosure and increasing their communication, reasoning and investigating skills for health promotion |
|                         |               |              |                 |                     |                          | Accountability             | 4. Insufficient expansion of transition planning                                      |                          |
|                         |               |              |                 |                     |                          |                             | 5. Cannot reveal students’ personal health information as they learn, so makes teaching the content difficult. |                          |
| 12. Gagnon, et al., 2016| Qualitative study | Canadian service providers | Not identified | Electronic personal health records | Use Access Disclosure | Confidentiality, Autonomy | 1. Confusion, lack of awareness | 1. Increased guidance for supporting staff and for defining ePHR, data ownership |
|                         |               |              |                 |                     |                          |                             | 2. Usability and relevance with system design                                     |                          |
|                         |               |              |                 |                     |                          |                             | 3. Weak user capacities and attitudes (i.e., patient health literacy, education and interest, support for professionals) |                          |
|                         |               |              |                 |                     |                          |                             | 4. Environmental factors (i.e., government commitment, and targeted populations)   |                          |
|                         |               |              |                 |                     |                          |                             | 2. Access to information and sharing of health records to inform stakeholders       |                          |
| Author       | Type of study | Participants | Country and law        | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified                                                                                           |
|--------------|---------------|--------------|------------------------|--------------------|--------------------------|---------------------------|-----------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------|
| Joffe, 2010  | Policy review | Applied for people for DD | Ontario Human Rights Commission Code | Health information | Collection                | Confidentiality Autonomy | 1. Lack of knowledge  
                      |                |              |                        |                        |                          |                                           | 2. Confusion- > which rights apply in which contexts  
                      |                |              |                        |                        |                          |                                           | 3. Complaints procedure: not enough support, and fear of reprisal from service providers                                           |
|               |                |              |                        |                        |                          |                                           | 1. Accessible and understandable information  
                      |                |              |                        |                        |                          |                                           | 2. Helping people to develop as self-advocates  
                      |                |              |                        |                        |                          |                                           | 3. Rights education outside of service provision: ensures confidentiality                                           |
|               |                |              |                        |                        |                          |                                           | 4. Provision of accommodations and supports to participate in Act  
                      |                |              |                        |                        |                          |                                           | 5. family member/friend support the person with disabilities                                                                 |
| Keith, 2004  | Commentary    | Not applicable | Canadian PIPEDA and USA privacy legislature | Personal information | Collection Use Access | Confidentiality           | 1. Unclear language  
                      |                |              |                        |                        |                          |                                           | 2. Lack of direction in Act  
                      |                |              |                        |                        |                          |                                           | 3. Stringent definition of personal information                                                                 |
|               |                |              |                        |                        |                          |                                           | 1. Clarity of purpose in collecting personal information  
                      |                |              |                        |                        |                          |                                           | 2. Consent  
                      |                |              |                        |                        |                          |                                           | 3. Limiting collection and use  
                      |                |              |                        |                        |                          |                                           | 4. Open to public review and compliance with requests for personal information access                                                                 |
| Rule, 2004   | Policy review | Not applicable | PIPEDA | Personal information | Collection Disclosure | Confidentiality           | 1. Lack of distinction between “strategic and consummatory privacy rights  
                      |                |              |                        |                        |                          |                                           | 2. Unknown or undefined risks  
                      |                |              |                        |                        |                          |                                           | 3. Logic of markets vs. logic of personal rights                                                                 |
|               |                |              |                        |                        |                          |                                           | 1. Clarify purposes for gathering and withholding information  
                      |                |              |                        |                        |                          |                                           | 2. Clarify how information is shared                                                                 |
| Author                  | Type of study                  | Participants                                           | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified                                                                 |
|------------------------|-------------------------------|--------------------------------------------------------|-----------------|---------------------|--------------------------|---------------------------|----------------------------------------------------------------------------------|----------------------------------------------------------------------------------------|
| 16. Beardwood, 2015    | Review                        | Not applicable                                         | PHIPA and PIPEDA, Canadian Digital Privacy Act USA EU | Personal health information | Disclosure (privacy breach) | Confidentiality, Accountability | 4. Manipulation of personal information connected to online transactions |
|                        |                               |                                                        |                 |                     |                          |                           | 5. Risks: profiling, matching, data mining                                      |                                                                                        |
|                        |                               |                                                        |                 |                     |                          |                           | Not identified                                                             |                                                                                        |
| 17. Clement, & Obar,   | Review                        | Canadian consumers of internet                         |                 | Personal data of customers | Use Disclosure            | Confidentiality             | 1. Each company report is idiosyncratic-hard to compare/understand company’s statistics |
| 2016                   |                               |                                                        |                 |                     |                          |                           | 2. Lack of transparency: retention periods for personal information, physical location of servers, data storage, and facilities where personal information is routed |
|                        |                               |                                                        |                 |                     |                          |                           | 1. Organizations knowingly contravening the Reporting Obligation or the Notification Obligation are guilty of punishable offense |
|                        |                               |                                                        |                 |                     |                          |                           | 2. Nothing unique or systemic required to report a privacy breach to Commissioner. |
|                        |                               |                                                        |                 |                     |                          |                           | 1. Transparency reporting sheds useful light on previously hidden practices |
| 18. Davidson, et al.,  | Comparative review of international legal frameworks | People with mental health problems                     |                 | Health information    | Collection Autonomy     |                           | 1. Laws based on mental disorder and risk, rather than decision-making ability |
| 2016                   |                               |                                                        |                 |                     |                          |                           | 2 Complex overlaps and some logical inconsistencies of guardianship and other |
|                        |                               |                                                        |                 |                     |                          |                           | Universal shifts from institutional to community-based care |
| Author          | Type of study | Participants | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified                                      |
|-----------------|---------------|--------------|-----------------|---------------------|-------------------------|----------------------------|------------------------------------------------------------------------------------|----------------------------------------------------------------|
| 19. Peekhaus, 2008 | National survey | General public | PIPEDA, PHIPA, and other provincial Health Information Acts | Health information and genetic data | Collection Use Confidentiality Autonomy | 1. Commercial exploitation of personal information 2. Domestic and international pressures for minimum standards of protection for personal information 3. Ministry of Health use of identifiable health information may not sit well with the Canadian public 4. Compounded safeguarding the privacy of medical information: as medical treatment migrates to complementary and alternative medicine | Willingness of Canadians (61%) to sharing their genetic information with family members |
| 20. Rose, & Rose, 2014 | Review of privacy law | Consumers of healthcare | PIPEDA, PIPA in Alberta and BC, Quebec Privacy Act, PHI, HIPAA and HITECH | Personal health information | Disclosure Confidentiality | None identified | None identified |
| 21. Seelig, 2006 | Case study     | HIPAA        | Access          | Confidentiality     | None identified          | None identified |
| Author                          | Type of study                                                                 | Participants                                                                                   | Country and law | Type of information | Privacy rights addressed | Ethical principle addressed | Barriers identified                                                                 | Facilitators identified |
|--------------------------------|-------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------|-----------------|---------------------|-------------------------|---------------------------|--------------------------------------------------------------------------------------|--------------------------|
| 22. Skouge, et al., 2007         | Description a model                                                           | Youth (24 years) with Angelman Syndrome Young adult in transition                            | None identified | Personal health information | Collection              | Confidentiality Autonomy   | None identified                                                                   | None identified          |
| 23. Moore, et al., 2016          | Full research report; mixed methods study                                     | Primary healthcare users in Southeastern Ontario Staff of disability service organization       | PIPEDA          | Personal health information | Collection              | Confidentiality          | None identified                                                                   | None identified          |
| 24. Wolbring, & Leopatra, 2013   | Cross-sectional study                                                         |                                                                                                 | PIPEDA          | Electronic health records | Collection              | Confidentiality Autonomy   | 1. Very limited control over the collection and safe keeping of personal information created over the course of participants lives 2. PI moderated through staff members | 1. Staff more skeptical towards certain sensor applications than others 2. Staff concerned over moderate control of own privacy and their client’s even lesser control over their privacy |
| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|------------------------|------------------|---------------------|-----------------|---------------------|----------------------|-----------------|--------------------|------------------------|
| Central East LHIN, 2009 | Final report-guidelines | Young adults in transitional age | Canada: PHIPA | Health information | Collection | Confidentiality | Autonomy | 1. Developmental disability identified as a barrier | 1. Client-centered care 2. Respect and avoidance of labels that stigmatize |
| Shimmell, & Gioia Di Vincenzo, 2017 | Professional guidelines: student guide | Occupational therapy students in placements | Canada: PIPEDA PHIPA | Personal information | Reference to Act | Confidentiality | None identified | None identified |
| Desai, 2013 | Final report-community mental health strategy and policy review | Service providers and criminalized person with mental health problems | Canada: PIPEDA PHIPA | Health information | Use Disclosure Access | Autonomy | 1. Families not considered as partner in care 2. Hesitancy to release client’s health information from agency files 3. No centralized information delivery model 4. Not enough consent policies for vulnerable populations with mental health issues | 1. Stricter rules on “circle of care” where consent is not required 2. Understanding the type of information that can be released by whom and how |
| Canadian Association for Community Living, 2011 | Policy review | Young adults with ID | CACL’s Vision 2020 | Health information | Collection | Autonomy | 1. Attaining full citizenship in law, policy, and practice 2. Institutional approach-insufficient access to educational aids/devices 3. Prejudice, poverty, lack of employment equality, lack of economic security for families 4. Lack of data collection on young people with DD | 1. Removal of stigma 2. Specialized services 3. New policies to regulate restraint use in residential services, and for reporting of violence/abuse against those with ID |
| Community Living-Huntsville, 2012 | Not applicable | Not applicable | Not identified | Personal information | Use | Confidentiality | None identified | 1. Stressing protection of privacy and |
| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|------------------------|------------------|---------------------|----------------|--------------------|-----------------------|------------------|--------------------|------------------------|
| 6. Ontario LAW: Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008 | Legislation review: Person with DD/ID | PIPEDA Disability Supports Act | Personal information | Collection Use Disclosure | None identified | confidentiality of personal information 2. Providing supervision in least intrusive manner, with respect for person’s right to privacy and dignity and ensuring safety and well-being 1. Limits on collection and use to no more than is reasonably necessary to meet the purpose |
| 7. Law Commission of Ontario: Background and Contexts in Which the Law Operates, 2017a | Policy review-chapter | Not applicable | PIPEDA | Information held in capacity registry | Collection Use Disclosure | Confidentiality Autonomy Accountability 1. Complying with privacy protections precludes persons from using informal supports and arrangements and makes it difficult for family members to obtain or share information 1. Formal substitute decision-making arrangements will give families greater access to supports or ease the difficulties of providing care 2. Use of informal network to assist decision-making |
Table 2 (continued)

| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|------------------------|------------------|---------------------|-----------------|---------------------|-----------------------|------------------|---------------------|-------------------------|
| 8. Law Commission of Ontario: Legal Capacity, Decision-making and Guardianship: Final Report, 2017b | Policy/legislation review and qualitative study | Not applicable | Health Care Consent Act, Substitute Decisions Act, Mental Health Act, | Personal information | Collection | Confidentiality Autonomy | 2. Checks and audits, and capacity assessment intrudes on privacy | 1. Vagueness in law 2. Formal assessment of capacity perceived as an invasion of privacy 3. Default role to family-not always involved |
| 9. Mental Health Commission of Canada, 2015 | Review of policy and literature | Emerging adults 16–25 years with mental health problems | PHIPA | Health information | Collection | Confidentiality | 1. Clinicians strictly adhering to altered legal status at 18 for confidentiality requirements | Clinicians being “family-engaged” |
| 10. Kindred Home Care, 2012 | Resource | Personal support workers | PHIPA | Health information | Use | Confidentiality | None identified | None identified |
| 11. Simcoe York Dual Diagnosis Education committee, 2015 | Resource | Families with persons with ID + mental health problems | PHIPA | Health information | Collection | Confidentiality | Lack of information regarding services/supports |
| 12. Wappel, 2007 | Policy review | Not applicable | PIPEDA, PHIPA | Personal information | Access (have information corrected) | None identified | 1. Lack of definition for “work product” 2. Confusion and lack of specificity between |

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| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|------------------------|------------------|---------------------|----------------|--------------------|----------------------|------------------|---------------------|-------------------------|
| 13. Wedge, 2014        | Dissertation     | Older persons       | PIPEDA         | Personal information | Collection           | Accountability     | expressed, implied, and opt-out 1. No means for privacy for those who suspect crime against older person to report | None identified |
| 14. Wellington North, 2015 | Meeting minutes | Not applicable      | PIPEDA         | Health information | Disclosure           | Confidentiality   | 1. Social media use 2. Lack of knowledge of PIPEDA | 1. Identify specific strategies for invasion of privacy 2. Only release health information according to legislation |
| 15. Community Living-Central Huron, 2015 | Policy document | Agency’s board of directors, staff, members-at-large and the people receiving service, and those with DD | PIPEDA | Personal information | Disclosure | Confidentiality | Not identified | None identified |
| 16. Office of the Privacy Commissioner, 2016 Annual Report to the Parliament | Report to the Parliament | Genetic testing users | PIPEDA | Personal information | Collection Disclosure (breach of information) | Confidentiality | 1. More information is collected: less adequate safeguards, increased risk and potential consequences of privacy breaches (related to genetic testing) 2. Cross border privacy issues increasing | Breach reports to OPC growing every year, (more since 2014) |
| 17. Kitchener Downtown Community | Client related policy document | All users of primary care, treatments, | PHIPA | Personal information | Collection Disclosure | Confidentiality | 1. Court order or subpoena | 1. Training staff to effectively communicate with |
| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|------------------------|------------------|---------------------|-----------------|--------------------|----------------------|-------------------|--------------------|------------------------|
| Health Centre, 2012    | referrals, health promotion | persons with disabilities |  | PHIPA | Health information | Disclosure | Accessibility | Confidentiality | people with disabilities. |
| 18. Legislative Assembly of Ontario: Review of the Personal Health Information Protection Act, 2008 | Committee documents/review | People including those with disability |  | PHIPA | Health information | Disclosure | Accessibility | Confidentiality | 1. Definition of “health information custodian” not entirely clear |
| 19. Ministry of Health and Long-Term Care (MOHLTC), 2006 | Service policy manual | Persons recovering from treatment, and elderly persons |  | PHIPA | Health information | Disclosure | Accessibility | Confidentiality | 1. Right to education for patients under the legislation (consent, breaches of privacy) |
| 20. Renfrew County Catholic District | Policy and procedure document | Service providers |  | PHIPA | Personal and health Information | Collection | None identified | None identified | None identified |
| Organization or author | Type of document | Population of focus | Country and law | Type of information | Privacy law addressed | Ethics addressed | Barriers identified | Facilitators identified |
|-----------------------|------------------|---------------------|----------------|--------------------|----------------------|------------------|---------------------|-------------------------|
| School Board, 2014    | Resource guide   | Ontario’s community literacy agencies on finances, administration and employment | PIPEDA | Personal information | Collection Use Disclosure | Confidentiality | None identified | None identified |
| Trottier & Kaattari, 2010 | Independent review | People in crisis | PHIPA | Individual’s healthcare information | Collection Use Disclosure | Confidentiality | 1. Constraints on information-sharing issues makes coordination between the TPS and the mental health system less effective | 2. Healthcare institutions must protect physician-patient confidentiality and sharing of healthcare information. |
| Luker, 2009          | News letter: College of Audiologists and Speech-Language Pathologists of Ontario | Persons with, hearing, speech, and language difficulties | PHIPA | Health information | Access (correction of information) | Confidentiality | None identified | None identified |
et al., 2016; Keith, 2004; Law Commission of Ontario (LCO) 2017a; Mills et al., 2003; Rule, 2004; Wappel, 2007), and a lack of integration of technology into policy (Mills et al., 2003) were cited often. The lack of international agreements and compliance with provincial and federal legislation in Canada, including respect for local norms around disability and privacy rights, was stated by several authors as problematic (Dyke et al., 2016; Geist, 2016; Mills et al., 2003; Siegel et al., 2009). Increasing levels of corporate lobbying interests and associated pressure to lower standards (Geist, 2016; Peekhaus, 2008) and exploitation of personal information (Peekhaus, 2008; Rule, 2004) were also cited as barriers.

On the other hand, facilitators of information privacy rights were also supported in the articles, primarily, the need for penalties to enforce accountability (Bearwood, 2015; Desai, 2013; Dyke et al., 2016; Geist, 2016; Joffe, 2010; Keith, 2004; LCO, 2017a; Wedge, 2014), but also increased acknowledgement and respect for disability (Canadian Association of Community Living (CACL), 2011; Community Living Huntsville, 2012; Central East Local Health Integrated Network (LHIN), 2009; Repetto et al., 2008), community, socioeconomic, and technology support (CACL, 2011; Joffe, 2010; LCO, 2017b), and higher standards for security of personal information (Community Living Huntsville, 2012; Peekhaus, 2008).

Exo Level: YADD and Community Interactions

At the exo level for adults with developmental disabilities, an interesting pattern of barriers and facilitators was evident consistently across articles. This related to access issues based in the interactions between YADD and their community and service providers. Barriers included insufficient knowledge leading to limited use of the existing legislation (Keith, 2004; Mental Health Commission of Canada (MHCC), 2015; Mills et al., 2003; Repetto et al., 2008; Rule, 2004; Simcoe York Dual Diagnosis Education Committee (SYDDEC), 2015; Wellington North, 2015), fear of reprisal for making a complaint (Joffe, 2010), lack of transparency regarding online social media platforms (Siegel et al., 2009; Rule, 2004), and use of overly

Fig. 2 Conceptual framework: determinants of privacy of personal information rights for YADD
complex language and presentation of rules (Siegel et al., 2009; Yalon-Chamovitz, 2009). Most noteworthy was the observation of a failure among organizations to provide appropriate accommodations to better support consent for collection and use of personal information and advocacy (Dyke et al., 2016; Joffe, 2010; Lafky & Horan, 2011; Larivie`re-Bastien & Racine, 2011; Mills et al., 2003; Wolbring, & Leopatra, 2013; Yalon-Chamovitz, 2009).

Facilitators identified at the exo level included increasing the use of advocacy supports by YADD and family caregivers (Joffe, 2010; Lafky & Horan, 2011; Mills et al., 2003), provision of technology for YADD to facilitate communication and comprehension (CAACL, 2011; Larivie`re-Bastien & Racine, 2011), and most importantly, the inclusion of family members to support decision-making (Chan, & O’Brien, 2011; Desai, 2013; LCO, 2017a, b; MHCC, 2015; Peekhaus, 2008). Finally, the addition of specific instructions, in professional practice and organizational guidelines, on how to support young adults with developmental disabilities to exercise their privacy rights was cited in all articles discussing interactions with YADD in the community (Kitchener Downtown Community Health Centre, 2012; Law Commission of Ontario, 2017a, b; Legislative Assembly of Ontario, 2008; Repetto et al., 2008; Wellington North, 2015).

**Meso Level: Organization-Based Factors**

Factors related to organizations and their processes, specifically to staff relations that act either as barriers or facilitators of access and utilization of privacy of information rights, were identified at the meso level. Barriers included a persistent lack of willingness on the part of organizations to share their information databases in order to ease the stress on YADD and their families (Clement, & Obar, 2016; Desai, 2013; Dyke et al., 2016; Gagnon et al., 2016; Larivie`re-Bastien, & Racine, 2011; Peekhaus, 2008; Mills, et al., 2003; Ministry of Health and Long-Term care (MHLTC), 2006; Lacobucci, 2014; Urowitz et al., 2008) and lack of commitment to use of technological advances to protect information privacy rights (Mills, et al., 2003; Siegel et al., 2009; Urowitz et al., 2008). Throughout the review, YADD needs were found to be unrepresented in organizational processes (Austin, 2006; CACL, 2011; Clement, & Obar, 2016; Siegel et al., 2009).

Identified solutions that acted as facilitators at the meso level focused on the provision of greater levels of experience, training, and practice opportunities for staff to better facilitate privacy rights for YADD (Dyke, et al., 2016; Gagnon et al., 2016; Lafky & Horan, 2011; Legislative Assembly of Ontario, 2008; Wellington North, 2015; Yalon-Chamovitz, 2009). As well, implementation of assessment of YADD needs for electronic health records and patient portals (Dyke et al., 2016; Urowitz et al., 2008) and enforcement of compliance among organizations in providing service that is consistent with existing privacy legislation and legislation governing the provision of individualized accommodations particularly for communication and comprehension (Austin, 2006; CACL, 2011; Dyke et al., 2016; Geist, 2016; Ontario Law, 2008).

**Micro Level: Individual Disability-Related Factors**

A few characteristics that stem from the individual’s disability were identified as barriers at the micro level. However, it is important to note that existing legislation already provides direction to avoid these barriers but is often overlooked due to lack of compliance with privacy legislation and community-based care (Beardwood, 2015; Davidson et al., 2016; Dyke et al., 2016; Geist, 2016; Joffe, 2010;). For instance, the failure to provide individualized accommodations YADD need to exercise their rights and receive support for their decision-making due to low literacy as well as communication, comprehension, and visual difficulties.
surfaced consistently through this review (CACL, 2011; Joffe, 2010; Larivie’re-Bastien, & Racine, 2011; Repetto et al., 2008; Yalon-Chamovitz, 2009). Similarly, a lack of support to better prepare YADD during this transition period was identified as a major vehicle for YADD to become more empowered in exercising their information privacy rights (Davidson et al., 2016; Joffe, 2010; Larivie’re-Bastien, & Racine, 2011; Repetto et al., 2008). Finally, socio-economic issues were cited as barriers to utilization of privacy rights, in that fees make it difficult for YADD and their families to make corrections to their personal information files (CACL, 2011; Laverie-Bastien, & Racine, 2011; Urowitz et al., 2008).

To better facilitate access and utilization of privacy rights for YADD, provision of support in two main areas were identified: (1) provision of training to improve computer literacy and self-advocacy skills specific to information privacy rights (CACL, 2011; Joffe, 2010; Repetto et al., 2008; Urowitz et al., 2008), and (2) provision of supported decision-making through greater engagement of family members in the consent process and utilization of privacy rights (CACL, 2011; Central East LHIN, 2009; Chan & O’Brien, 2011; Davidson et al., 2016; Lafky & Horan, 2011; LCO, 2017a, b; Joffe, 2010; Repetto et al., 2008).

Recommendations

The findings and discussions of these articles show that the gap between the existing legislation and access to, or utilization of, information privacy rights among YADD and their families results from three factors: (1) a lack of knowledge among YADD and their family supporters (Gagnon et al., 2016; Joffe, 2010; Lacobucci, 2014; Lafky & Horan, 2011; Repetto et al., 2008; Yalon-Chamovitz, 2009), (2) a tendency of organizations to interpret or adhere to privacy laws inconsistently (Clement & Obar, 2016; Desai, 2013; Dyke et al., 2016; Geist, 2016; Peekhaus, 2008; Wolbring & Leopatra, 2013; Urowitz et al., 2008), and (3) a lack of access to the tools needed to support YADD exercising their information privacy rights (Davidson et al., 2016; Joffe, 2010; Larivie’re-Bastien & Racine, 2011; Mills et al., 2003; Repetto et al., 2008; Skouge et al., 2007; Urowitz, et al., 2008; Yalon-Chamovitz, 2009).

In connection with the findings reviewed, we recommend the following three areas that need to be addressed by privacy commissioners and organizations supporting young adults with developmental disabilities. First, and foremost, awareness, knowledge, and skills need to be raised among organizational staff, families, and YADD. In this way, self-advocacy will occur more frequently, and families will be included in the YADD’s core support and privacy rights education in their high school curriculum. Second, promotion of information privacy legislation through education for organizational staff is required. In particular, implementation of manuals with specific guidelines instructing staff with strategies to use the privacy legislation is suggested. Finally, targeted translation of existing legislation that will allow more YADD and their families to exercise their privacy of information rights is recommended.

Limitations

This review has some limitations. Our literature search was limited to articles focusing on privacy legislation and developmental disabilities, and this search strategy may have contributed to excessively narrow range of articles included. Several exceptions for inclusion were established to capture relevant articles and to make it possible to broaden
the capture of relevant barriers and facilitators also relevant to YADD. The articles differed not only in their objectives and methodology or type of article, but also showed great heterogeneity in approach to considering the issue of privacy of information rights. While quality was consistently high (such as representative samples, standardized tools, in depth policy discussion), the total number of empirical studies was very few \( (n = 6) \). It is important that future studies examine public understanding of privacy rights and pathways to accessing tools to exercise privacy rights. Finally, the presentation of our findings in Fig. 2 (Conceptual Framework: Determinants of Privacy of Personal Information Rights for YADD) presents a systems perspective. Our interpretation of our findings is influenced by this perspective.

**Conclusion**

In this scoping review, 24 peer-reviewed articles and 23 articles from the gray literature were identified which examined the barriers and facilitators for access and utilization of information privacy rights in relation to the needs of young adults with developmental disabilities and their families. A basic requirement in protecting individual privacy rights is informing people of their rights so they know when a violation has occurred and how it can be remedied. This becomes a challenge to organizations trying to support families and their YADD as communication and information sharing can be complicated, often requiring accommodations or supports for the decision-making. The implications of the challenges typically experienced by YADD are tremendous, especially for providing support for provision of consent and decision-making to ensure ensuring confidentiality and autonomy throughout the protection of personal information privacy (Joffe, 2010). Although some parallels can be made with elderly citizens or persons with physical disabilities, important and distinct differences exist for YADD whose chronological age indicate adult, but who may not have sufficient decision-making capacity, and, more often than not, may be restricted as a result of their mode of communication or literacy level. By the time the potential privacy breach is voiced, or even recognized, young adults with developmental disabilities may have already lost some of their privacy rights in the process. For this reason, and because existing privacy legislation exists, the present review suggests that increasing awareness, education, and knowledge translation tools for all involved, especially YADD, family caregivers, and service providers, will help to combat the disadvantage in exercising information privacy rights by young adults with developmental disabilities.

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**Compliance with Ethical Standards**

**Conflict of Interest** The authors declare that they have no conflict of interest.

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References

Arksey, H., & O’Malley, L. (2005). Scoping studies: towards a methodological framework. Journal of Social Research Methodology, 8, 19–32.

Austin, L. (2006). Is consent the foundation of fair information practices? Canada’s experience under PIPEDA. The University of Toronto Law Journal, 56(2), 181–215.

Beardwood, J. (2015). The new Canadian digital privacy act: the good, the bad and the ugly. new legislation creates new problems as it fixes others. CRI, 129–134.

Bronfenbrenner, U., & Ceci, S. (1994). Nature-nurture reconceptualized in developmental perspective: a bioecological model. Psychological Review, 101(4), 568–586.

Canadian Association for Community Living. (2011). Inclusion of Canadians with intellectual disabilities. Toronto: CACL Retrieved from http://www.cacl.ca/sites/default/files/National%20Report%20Card%202013%20ENG%20Final.pdf.

Central East Local Health Integration Network. (2009). Final Report. Early youth interventions project report. Transitional Age Youth and Health Promotion, Ontario: Central East LHIN Retrieved from http://www.canadian-patient-consent-form.com/form/86347912-Full-Report-Central-East-LHIN.

Chan, B. W., & O’Brien, A. M. (2011). The right of caregivers to access health information of relatives with mental illness. International Journal of Law and Psychiatry, 34(6), 386–392.

Clement, A., & Obar, J. A. (2016). Keeping internet users in the know or in the dark an analysis of the data privacy transparency of Canadian internet carriers. Journal of Information Policy, 6, 294–331.

Colquhoun, H. L., Levac, D., O’Brien, K. K., Straus, S., Tricco, A. C., & Perrier, L. (2014). Scoping reviews: time for clarity in definition, methods, and reporting. Journal of Clinical Epidemiology, 67(12), 1291–1294.

Community Living-Central Huron. (2015). Community living-Central Huron policies & procedures. Ontario: CL-CH Retrieved from http://www.clch.ca/policy.

Community Living- Huntsville. (2012). Section policies & procedures. Policy title service records and retention. Ontario: Community Living-Huntsville Retrieved from http://www.clhuntsville.ca/wp-content/uploads/2014/02/Policy-and-Procedures.pdf.

Davidson, G., Brophy, L., Campbell, J., Farrell, S. J., Gooding, P., & O’Brien, A. (2016). An international comparison of legal frameworks for supported and substitute decision-making in mental health services. International Journal of Law and Psychiatry, 44, 30–40.

Desai, A. (2013). Towards an integrated network (second edition): working together to avoid criminalization of people with mental health problems. Ottawa, ON: St. Leonard’s Society of Canada.

Developmental Services Ontario. (2016). What is a developmental disability? Ontario: DSO Retrieved from: http://www.dsontario.ca/whats-a-developmental-disability.

Dyke, S. O. M., Saulnier, K. M., Pastinen, T., Bourque, G., & Joly, Y. (2016). Evolving data access policy: the Canadian context. Facets, 1(1), 138–147.

Fogden, B., Thomas, S., Daflern, M., & Ogloff, J. (2016). Crime and victimisation in people with intellectual disability: a case linkage study. BMC Psychiatry, 16, 170.

Gagnon, M.-P., Breton, E., Fortin, J.-P., Khoury, L., Dolovich, L., Price, D., Wiljer, D., Bartlett, G., & Archer, N. (2016). Adoption of electronic personal health records in Canada: perceptions of stakeholders. International Journal of Health Policy Management, 5(7), 425–433.

Geist, M. (2016). The policy battle over information and digital policy regulation: a Canadian perspective. Theoretical Inquiries in Law, 17, 415–449.

Joffe, K. (2010). Enforcing the rights of people with disabilities in Ontario’s developmental services system. In The Law as it affects persons with disabilities. Ottawa: Law Commission of Ontario.

Keith, B. C. (2004). Privacy north of the border: 10 things you should know about Canadian personal information laws. American Bar Association, Business Law Section, 14(2). Retrieved from http://www.americanbar.org/content/dam/aba/publications/blt/2004/11/privacy-north-of-border-200411.authcheckdam.pdf.

Khanlou, N. (2018). Final report: Developmental services research Grant Fund. Toronto: York University.

Khanlou, N., Haque, N., Mustafa, N., Vazquez, L. M., Mantini, A., & Weiss, J. (2017a). Access barriers to services by immigrant mothers of children with autism in Canada. International Journal of Mental Health and Addiction, 15(2), 239–259.

Khanlou, N., Mantini, A., & Degendorfer, K. (2017b). The YADD privacy project: improving privacy for young adults with developmental disabilities through research and innovative knowledge translation. Toronto: York University.

Khanlou, N., Mustafa, N., Vazquez, L. M., Davidson, D., & Yoshida, K. (2017c). Mothering children with developmental disabilities: a critical perspective on health promotion. Health Care for Women International, 38(6), 613–634.
Kindred Home Care. (2012). *Life at home just got better: providing kindred care*. New Brunswick: KHC.

Retrieved from kindredhomecare.com/wp-content/uploads/2012/10/KHC-Training-Textbook-Sample.pdf.

Kitchener Downtown Community Health Centre. (2012). *Kitchener downtown community health Centre: client related policies*. Kitchener, ON: KDCHC Retrieved from http://www.kdchc.org/wp-content/uploads/2012/02/Client-Policies-Web-2.pdf.

Labov, F. (2014). Police encounters with people in crisis: an independent review. Toronto Police Service, 1–413.

Lafky, D. B., & Horan, T. A. (2011). Personal health records: consumer attitudes toward privacy and security of their personal health information. *Health Informatics Journal*, 17(1), 63–67.

Larivière-Bastien, D., & Racine, E. (2011). Ethics in health care services for young persons with neurodevelopmental disabilities: a focus on cerebral palsy. *Journal of Child Neurology*, 26(10), 1221–1229.

Law Commission of Ontario. (2017a). *Background and contexts in which the law operates*. Toronto: LCO Retrieved from https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/legal-capacity-decision-making-and-guardianship-discussion-paper-2/i-background-and-contexts-in-which-the-law-operates-2/.

Law Commission of Ontario. (2017b). *Legal capacity, decision-making and guardianship: final report*. Toronto: LCO Retrieved from https://www.lco-cdo.org/en/our-current-projects/legal-capacity-decision-making-and-guardianship/.

Legislative Assembly of Ontario. (2008). *Committee documents: standing committee on social policy - 2008-Aug-28—review of the Personal Health Information Protection Act, 2004*. Ottawa, ON: Legislative Assembly of Ontario Retrieved from http://www.ontla.on.ca/web/committee-proceedings/committee_transcripts_details.do?locale=en&Date=2008-08-28&ParlCommID=8785&BillID=&Business=Review+of+the+Personal+Health+Information+Protection+Act%2C+2004&DocumentID=23176#P84_5361.

Luker, K. (2009). The age of the electronic health record. *CASLPO Today*, 7(3), 13–17.

Mental Health Commission of Canada. (2015). *Taking the next step forward: Building a responsive mental health and addictions system for emerging adults*. Ottawa, ON: MHCC.

Mills, S. K., Yao, R. S., & Chan, Y. S. (2003). Privacy in Canadian health networks: challenges and opportunities. *Leadership in Health Services*, 16(1), 1–10.

Ministry of Health and Long-Term Care. (2006). *Community care access centres: client services policy manual*. Toronto: MHILC Retrieved from http://www.ontla.on.ca/library/repository/mon/26004/316651.pdf.

Moore, K.M., Belanger, P., & Biro, S. (2016). Understanding health inequities and access to primary health care in Southeastern Ontario. Retrieved from http://www.kflaphi.ca/wp-content/uploads/HealthInequities_FullReport.pdf.

Office of the Privacy Commissioner. (2016). 2015–2016 annual report to parliament on the personal information protection and electronic documents act and the privacy. Gatineau, QC: OPC Retrieved from https://www.priv.gc.ca/en/ocp-actions-and-decisions/ar_index/201516/ar_201516/.

Ontario Law. (2008). *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008*, S.O. 2008, c. 14. Ontario: Ontario Law Retrieved from https://www.ontario.ca/laws/statute/08s14.

Peekhaus, W. (2008). Personal health information in Canada: a comparison of citizen expectations and legislation. *Government Information Quarterly*, 25, 669–698.

Personal Health Information Protection Act (PHIPA), 2004, SO 2004, c 3, Sch A. (2004). Retrieved from: http://canlii.ca/t/53154.

Personal Information Protection and Electronic Documents Act (PIPEDA), SC 2000, c 5. (2000). Retrieved from: http://canlii.ca/t/52hm.

Repetto, J. B., Gibson, R. W., Lubbers, J. H., Gritz, S., & Reiss, J. (2008). Practical applications of confidentiality rules to health care transition instruction. *Remedial and Special Education*, 29(2), 118–126.

Renfrew County Catholic District School Board. (2014). *INDEX: administration policies & procedures. Appropriate use of technology guidelines*. Renfrew, ON: RCCDSB Retrieved from: https://drive.google.com/file/d/1RJyTkV_X433H4mdT2zvim3DGQFznQOp/view, Index.

Roebuck, R., Paquet, M. & Coutles-Macleod, J. (2008). Improving health outcomes for children and youth with developmental disabilities. Retrieved from: http://www.surreyplace.on.ca/documents/Resources/Children’s%20Forum%20Literature%20Review_final(web).pdf.

Rose, R. V., & Rose, L. H. (2014). Appreciating health data privacy laws in Canada, the United Kingdom, and the United States. *The EDP Audit, Control, and Security Newsletter*, 49(5), 18–24.

Rule, J. B. (2004). Toward strong privacy: values, markets, mechanisms and institutions. *University of Toronto Law Journal*, 34(2), 183–225.

Seelig, R. (2006). New technology provides urgent medical information and protects privacy; providing important information in medical situations for the developmentally disabled. *The Exceptional Parent*, 36(5), 47–51.
Shimmell, L., & Gioia Di Vincenzo, G. D. (Eds.). (2017). Master of science occupational therapy MSc (OT). Clinical education handbook. Hamilton, ON: McMaster University, Faculty of Health Sciences.

Siegel, A., Denny, W., Poff, K. W., Larose, C., Hale, R., & Hintze, M. (2009). Survey of privacy law developments in 2009: United States, Canada, and the European Union. The Business Lawyer, 65(1), 285–307.

Simcoe York Dual Diagnosis Education Committee. (2015). Supports and services for persons with a dual diagnosis: a resource manual for York region families. Simcoe York, ON: SYDDEC Retrieved from http://www.community-networks.ca/wp-content/uploads/2015/11/central-york-ddx-resource-guide.pdf.

Skouge, J.R., Kelly, M.L., Roberts, K.D., Leake, D.W., & Stodd, R.A. (2007). Technologies for self-determination for youth with developmental disabilities. Education and training in developmental disabilities, 42(4), special conference issue research to practice, 475–482.

Tricco, A., Lillie, E., Zarin, W., O’Brien, K., Coquohoun, H., Kastner, et al. (2016). A scoping review on the conduct and reporting of scoping reviews. BMC Medical Research Methodology, 16(15), 1–10.

Trottier, V. & Kaattari. J. (2010). Capacity Plus: Organizational Capacity Resource Guide for Ontario’s Community Literacy Agencies. Community literacy of Ontario. Retrieved from http://www.communityliteracyofontario.ca/wp/wp-content/uploads/2013/08/capacity_plus_book_02.pdf.

Urowitz, S., Wiljer, D., Apatu, E., Eysenbach, G. DeLenardo, C, Harth, T., Pai, H., & Leonard, K.J. (2008). Is Canada ready for patient accessible electronic health records? A national scan. BMC Medical Informatics and Decision Making, 8(33), 1–7.

Wappel, T. (2007). Statutory review of the personal information protection and electronic documents act (PIPEDA): 4th report of the Standing Committee on Access to Information, Privacy and Ethics /. Standing Committee on Access to Information, Privacy and Ethics, 2007. Retrieved from https://search.library.utoronto.ca/details?6228520.

Wedge. (2014). Enduring powers of attorney and financial abuse of older persons are existing safeguards sufficient? Retrieved from http://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.855.5092&rep=rep1&type=pdf.

Wellington North. (2015). Admin. & finance committee meeting minutes. Retrieved from https://wellingtonnorth.com/content/government/committees-of-council/administration-finance-committee/2015-agendas-minutes/12-17-2015-administration-finance-minutes.pdf.

Wolbring, G., & Leopatra, V. (2013). Sensors: views of staff of a disability service organization. Journal of Personalized Medicine, 3, 23–39.

Yalon-Chamovitz, S. (2009). Invisible access needs of people with intellectual disabilities: A conceptual model of practice. Intellectual and Developmental Disabilities, 47(5), 395–400.