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Children with Intellectual Disability and Their Experience with Fecal Incontinence: Beyond a Pathophysiology Approach

Les enfants ayant une déficience intellectuelle et leur expérience de l'incontinence fécale : Au-delà d'une approche physiopathologique.

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Abstract

Compared to children without intellectual disability (ID), children with ID are significantly more likely to experience fecal incontinence. Within the dearth of extant research about fecal incontinence, children with ID are often excluded from studies. Researchers of studies including children with ID often understand fecal incontinence as either a "normal" and involuntary diagnostic phenotype for children with ID or as a deliberate oppositional behaviour. In either case, the child is positioned as the focus of the problem. In this article we discuss how children with ID experience fecal incontinence within a context of disabling service barriers resulting from the children's individualized method of communication and self-care support needs that further their social stigmatization. This concept emerged from a Foucauldian discourse analysis that we conducted with eight carers of children with ID in Ontario. The results that we have presented in this article only discuss the interrelated concepts of "fecal incontinence," "needs, and "untouchable as a social consequence" that emerged from theme 1 of the full study. Future research is needed to explore the experience of children with ID and fecal incontinence from a holistic perspective and to inform professionals working with this population about the importance of providing person-centred interventions.

Résumé

Comparativement aux enfants qui n'ont pas de déficience intellectuelle (DI), les enfants ayant une DI sont significativement plus susceptibles de vivre de l'incontinence fécale. Dans le contexte d’un manque de recherches existantes sur l'incontinence fécale, les enfants ayant une DI sont souvent exclus des études. Les chercheurs d'études incluant des enfants ayant une DI comprennent souvent l'incontinence fécale soit comme un diagnostic phénotypique « normal » et involontaire pour les enfants ayant une DI, soit comme un comportement d'opposition intentionnel. Dans tous les cas, l’enfant est placé au cœur du problème. Dans cet article, nous discutons de la façon dont les enfants ayant une DI vivent l'incontinence fécale dans un contexte d'obstacles aux services qui leurs sont destinés résultant de la méthode de communication individualisée des enfants et des besoins de soutien aux autosoins qui renforcent leur stigmatisation sociale. Ce concept a émergé de l’analyse foucaldienne d’un discours mené en Ontario auprès de huit donneurs de soins d'enfants ayant une DI. Les résultats présentés dans cet article ne traitent que des concepts interreliés d'« incontinence fécale », de « besoins » et d'« intouchable en tant que conséquence sociale » qui ont émergé du premier thème de l'étude complète. Des recherches futures sont nécessaires afin d’explorer l'expérience d’enfants ayant une DI qui vivent de l'incontinence fécale d'un point de vue holistique et pour informer les professionnels travaillant avec cette population de l'importance de fournir des interventions centrées sur la personne.

Mots-clés : déficience intellectuelle, incontinence fécale, enfants

Introduction

This first section introduces the concepts of intellectual disability (ID) and fecal incontinence. We use the American Psychiatric Association’s (APA; 2013) definition of intellectual disability (ID): a neurodevelopmental disorder that originates in the developmental period and causes impairment to a person’s intellectual and adaptive functioning. It is also important to introduce readers to definitions of fecal incontinence which include theories about both the physical and psychological causes of fecal incontinence~~.~~ The Mayo Clinic (2020) explains fecal incontinence from the physical perspective as:

> …The inability to control bowel movements, causing stool (feces) to leak unexpectedly from the rectum. Fecal incontinence ranges from an occasional leakage of stool while passing gas to a complete loss of bowel control. Common causes of fecal incontinence include diarrhea, constipation, and muscle or nerve damage. (https://www.mayoclinic.org/diseases-conditions/fecal-incontinence/symptoms-causes/syc-20351397)

Other organizations define and explain fecal incontinence as an involuntary disorder caused by constipation, or a voluntary disorder associated with psychological problems. The APA has defined fecal incontinence or “the passage of feces into inappropriate places” (Encopresis Diagnostic Criteria section, para. 1) as an elimination disorder, diagnosed as encopresis, with subtypes of with or without constipation (APA, 2013). The APA associated concept of encopresis with constipation is considered to be an “involuntary” action of a child, whereas encopresis without constipation is suggested to be “voluntary” and “intentional” as a potential symptom of a conduct disorder.

Similarly, the Rome IV categorized fecal incontinence as either a diagnostic criterion of fecal constipation that occurs as involuntary overflow or as a diagnostic criterion of non-retentive fecal incontinence that may be associated with behavioural, emotional, or learning problems (Hyams et al., 2016). The Rome IV is a handbook of diagnostic criteria of functional gastrointestinal disorders, formulated according to recommendations made by the Rome foundation committees, specialized in specific gastrointestinal disorders (Drossman et al., 2016). We have introduced the APA and Rome IV diagnostic approaches to fecal incontinence because researchers often use the terms "encopresis" and "fecal incontinence" interchangeably and include both within their literature search strategies (Niemczyk et al., 2018; Roozen et al., 2017). Further, Matson and LoVullo (2009) have suggested that inconsistent use of diagnostic terminologies and sub-categorizations, and their inconsistent application, have created challenges for clinicians and researchers to understand the problem of fecal incontinence. To be noted is that both the APA and Rome IV diagnostic approaches pertain to individuals who have reached a developmental age of four years which many children with ID do not.

Children with ID experience a higher prevalence of fecal incontinence than children without ID (Joinson et al., 2006; Matson & LoVullo, 2009; Niemczyk et al., 2017; Wagner et al., 2017). Children with ID also experience a higher prevalence of fecal incontinence persisting into adulthood (von Wendt et al. 1990; Voskuijl et al., 2006). It is these striking observations which inspired the research described in the present study.

Background

Extant literature about fecal incontinence is limited by primarily including children who are typically developing and excluding children with ID. Further, there is a dearth of literature specific to the experience of children with ID with fecal incontinence despite the prevalence of fecal incontinence. This has been found to be significantly higher for children with ID, and for other syndromes that have an ID comorbidity, compared to children without ID (Justine Niemczyk et al., 2016; Roozen et al., 2017; von Wendt et al., 1990; Wagner et al., 2017; Witmer et al., 2019). Huntley and Smith (1999) proposed that fecal incontinence is often assumed to be a "normal" behavioural phenotype of persons with ID (p. 484). Researcher or healthcare provider diagnostic overshadowing, or attributing a child's fecal incontinence as a characteristic of ID rather than exploring other possible causes of fecal incontinence (Ouellette-Kuntz et al., 2005), may also contribute to the exclusion of children with ID as participants in research exploring fecal incontinence or research specific to understanding fecal incontinence in children with ID. For example, many researchers excluded children with ID from participating in studies about fecal incontinence, listing ID as an organic cause of fecal incontinence or not explaining the exclusion of children with ID (Akdemir et al., 2015; Bekkali et al., 2010; Çengel-Kültür et al., 2014; Esposito et al., 2013; Mattheus et al., 2021; Voskuijl et al., 2006). (The term organic refers to the fact that anorectal malformations or neurogenic abnormalities can cause the incontinence as opposed to other factors referred to as functional.) We suggest that researchers may have excluded children with ID based on the assumption that all children with ID fall below the APA and Rome IV diagnostic criteria of having reached a developmental age of four years old.

In a qualitative study, using Foucauldian discourse analysis, we explored how carers of children with ID and governmental agencies understood children with ID to better understand service navigational barriers (Don, 2019). In this paper, we presented our unexpected finding that carers identified fecal incontinence as both a distressing intrinsic characteristic of ID and as a consequence of disabling service barriers (see Don (2019, p. 93) for a summary of interview themes and subthemes). Discourse analysis involves the collection and analysis of written and/or spoken language in specified ways. Researchers apply Foucauldian discourse analysis to explore the discourses that inform societal knowledge and truths about children with ID, map the effects of these discourses within power relations, and situate a nuanced way to question the status quo (Powers, 2013).

Overview of Foucauldian Discourse Analysis

Foucauldian discourse analysis uses a post-structural lens through which truth is viewed as being socially, politically, and historically constructed and changing over time (Meleis, 2012; Mertens, 2005). Deleuze and Guattari (2011) explained that what society believes to be true about certain groups of people derives from the continual and ever-changing stratification process. The stratification process sorts and orders a population into distinguished categories and groups according to what society believes to be true about what is a normal and ideal person (Deleuze & Guattari, 2011). Foucault understood discourse, not in a strictly linguistic way. Instead, he explained that discourse is the meaning and way that society understands something, and is formulated through the interaction of power relationships within society, development of knowledge, and accepted truths (M. Foucault, 1972; Lupton, 1992). Discursive meaning is one way of understanding how truths in society are formed and create order. Foucault did not provide a specific procedural guide to conduct discourse analysis. Many authors have developed methods of Foucauldian discourse analysis, distinguished in part by their situated paradigm and perspectives on types of included data (Potter, 2004; Powers, 2001). For our Foucauldian analysis study, we utilized Powers (2001) method of Foucauldian inspired discourse analysis. Powers (2001) approach involves a structural analysis through which, researchers critically examine the discourse from the data by applying questions formulated by Rawlinson (1987) from Foucault's writings about how discourse formation to "understand how discourse functions presently" (Powers, 2013, p. 7). Powers (2001) method also includes a power analysis of the data that involves applying questions that flesh out how discourses function within relationships between people (Powers, 2013, p. 7). The researcher's objective is to formulate a thorough interpretation of the data to address the research questions and stimulate nuanced discussions and debates to locate areas for change (Powers, 2001, 2013).

Research Objectives

In the full study, we addressed the following research questions: (1) How do carers of children with ID and governmental agencies understand ID? (2) What are the discourses that inform these social understandings of ID? (3) What are the materializations of these understandings? and (4) How do services users and providers exercise power within service user-provider relationships? From a Foucauldian perspective, materializations are the physical and social structures that result from discourse and how society recognizes and understands a thing or concept (Dreyfus & Rabinow, 1983, p. 90). In the present paper, we present the unexpected findings of the interrelated concepts of "fecal incontinence," "needs," and "untouchable as a social consequence" that emerged from theme 1 of the full study (Don, 2019).

Methods

Participants

We included carer participants who were parents or permanent adoptive families, for more than one year, of children with ID between the ages of six and 14. Children with ID residing in Ontario often experience service transition at the age of six, from intensive early intervention services to other service delivery models commonly provided by school boards and developmental agencies (Ministry of Education of Ontario, 2017). Youth aged 14 and above also experience service transition preparation for their transition to adulthood and the adult service system (Ministry of Education of Ontario, 2017). Additionally, we included carers residing in a primarily rural, region of Eastern Ontario associated with disproportionate rates of poverty and vulnerable early development scores; and primary care provider reports of experiencing challenges navigating services for their pediatric patients with ID (Don & O'Byrne, 2012; Parent Resource Centre, 2014; Statistics Canada, 2011).

Materials

We developed an interview guide that included prompting grand tour questions asked to initiate dialogue (Creswell, 2013; Potter & Wetherell, 1987). See also Don (2019, p. 222.). Guided by the research questions, we used thematic analysis to organize the text into analysable segments, codes, and finally themes (Guest et al., 2012). Powers’ (2001) analytical framework for discourse analysis was then used to theoretically analyse the data themes and guide interpretation and discussion of the study findings. Powers’ (2001) framework includes questions to guide researchers to conduct a structural and power analysis of themed data. Powers’ (2001) book *The Methodology of Discourse Analysis* includes the full list of these analytic questions (pp. 56-62).

Procedure

Case managers from a developmental service centre, with the approval of the agency’s director, distributed and offered to read study information letters to families at home visits to ensure equitable access to the study information for carers with diverse literacy abilities. We also attended a community sports practice for two weeks and distributed the study information letter to interested carers of athletes. Carers interested in participating in the study either contacted us by telephone, email, or face to face at the sports practice.

We recruited eight carer participants within this study. All participants provided written informed consent to participate in the study and to allow us to audio record the interviews. We conducted four interviews one-on-one with carers and two interviews where two carers from one family were present together, with a total of eight participants. Five carers, within four interviews (i.e., three individual carers and one pair of carers from the same family), discussed the challenges that their child with ID experienced with fecal incontinence.

We conducted semi-structured interviews using the interview guide. Open-ended, follow-up questions and probes emerged from participant responses to the broad questions, were used to explore, expand, and compare topic areas discussed by participants (Creswell, 2013; Potter & Wetherell, 1987). We transcribed the interviews with emphasis on maintaining the highest resolution by transcribing verbatim all speakers' contributions and notating nonverbal events to retain the context and depth of the conversation to provide a rich text to analyse (Potter & Wetherell, 1987).

We analysed the interview transcripts using thematic analysis as a procedural guide to organize the text into analysable segments. We used thematic analysis alongside and congruent with the Foucauldian discourse analysis approach by using the research questions to guide the analysis and searching for similarities, contradictions, and emerging relationships (Guest et al., 2012; Powers, 2001). We segmented the text into units of meaning using a highlighter, then tagged "key words and/or phrases" (Guest et al., 2012, p. 51). We clustered tags with similar meaning or topics into codes and then input the codes, and their tags into an excel spreadsheet and clustered them into themes (Guest et al., 2012).

We conducted a discourse analysis of the data themes using Powers' (2001) analytic framework, including structural and power analysis to guide theoretical interpretation of the findings and guide the discussion.

We determined the study sample size through an emergent approach that included constant comparison of the collected and analysed data to identify when theoretical saturation had been reached. Theoretical saturation is during following the researcher iteratively analysing the collected data and determining that it thoroughly reflects contrasting and similar discourses from which the researcher can formulate nuanced answers to the research questions (Jager & Meyer, 2012; Phillips & Hardy, 2002; Powers, 2001). Authors of Foucauldian discourse analysis methods advise researchers to strive for theoretical saturation because the objective of this methodology is to generate research results that provide nuanced understandings and interpretations of discourses, and identify potential areas for change, understanding that discourse that is not static but continuously changes within a particular socio-political context (Phillips & Hardy, 2002; Potter & Wetherell, 1987; Powers, 2001).

The study criteria of rigour were thoroughness, congruence, and reflexivity. We demonstrated the criteria of thoroughness by providing a clear description of the theoretical framework and processes of data collection and analysis and including sufficient raw data through the inclusion of direct quotes to allow readers to appraise our interpretations from the data analysis (Crowe, 2005; Madill et al., 2000; Phillips & Hardy, 2002). I (primary author) exercised reflexivity through declaring my speaking position as a middle-class parent of a person with an ID and recognizing that we all stand within a discourse that contributes to how we produce our research (Jager & Meyer, 2012; Lupton, 1992; Smith, 2007). We also engaged in peer debriefing about our methodological decision-making and interpretations. We established the internal coherence of the study by selecting and clearly outlining compatible research questions, our overarching paradigm, theoretical framework, and selected approach of discourse analysis (Crowe, 2005; Lupton, 1992; Nixon & Power, 2007). The University of Ottawa Research Ethics Board approved this study (File number H10-14-09).

Results

Eight carers of children with ID participated in this study: five biological mothers, one adoptive mother, one grandmother who was a guardian, and one father. We identified three interview themes from the Foucauldian discourse analysis: defining ID, diagnostic processes, and materializations. This article will only discuss the interrelated concepts of "fecal incontinence," "needs," and "untouchable as a social consequence" that emerged from the first theme, defining ID, in which carers spoke about how they understood ID, including fecal incontinence as a category. Carers spoke about their children's fecal incontinence as evidence of their child's capacity to willfully exhibit challenging behaviour of fecal incontinence, and also described fecal incontinence as an intrinsic characteristic of ID. Carers also described their children's incontinence experiences as expressions of their children's needs regarding their impairments in verbal communication and self-care not being met. Carers associated that their children experienced social stigmatization and rejection from their experiences with fecal incontinence.

Fecal Incontinence

Five of the carers described their children's experiences with fecal incontinence, not reported to be associated with constipation. Carers perceived that their children's fecal incontinence was, in part, a challenging behaviour. One carer described how her child could defecate on the toilet and independently clean himself but often defecated in his underwear. She stated:

> He's got his underwear right in a drawer. He won't use them. He'll use them, but he'll dirty them. He'll sit right in it too because he doesn't want to tell anybody… He's always being trained… he gets angry that he has to go clean it… There's nothing wrong with him. He's been tested… He knows to do it [defecate on toilet]… He's done it for so long he doesn't care now.

Another carer discussed her frustration, in part, with her child when she was called to the school because he had been incontinent and then spread feces on himself. She described what she saw and her actions when she arrived at the school.

> "…he had pooped, and he stuck his hands in it [at school]… I looked at him and said, 'You, get in the bathroom.' And he walked right to the bathroom… he knows when I say it- that's enough."

The carers located the issue of fecal incontinence, in part, as a problem with their children who had some capability and understanding to be continent but chose not to. The carers implied that their children had a degree of capacity to decide to be continent or not. At the same time, the carers identified that their children also needed practical support from others to be continent.

Needs

The carers more often described situations in which their children did not receive the service support and assistance that they required to be continent. The carers perceived that service providers acted as barriers to their children either being continent or being supported following incontinence. One carer described how her son's teacher did not understand or inquire to understand her child's attempt to verbalize his need to defecate, leading to her son being incontinent. She stated:

> …he's very good at echolalia, using it properly so it makes sense and if you don't know where it's coming from you think it's him telling you something. It's not really what he's trying to say it's just something sort along the lines of what he's trying to say. For

> example, he'd tell the teacher he'd pooped his pants. She would call home right away. By the time that I'd got there, of course, he did [fecal incontinence], ***but he had to go to the bathroom***… if she had just let him go to the bathroom, I wouldn't have had to go and change him and everything else.

The carer's description of the above encounter highlights that the child's experience of fecal incontinence was associated with his impaired ability to communicate his need to be permitted to use the bathroom using typical social norms of verbal phrasing. The teacher understood that the child required assistance related to fecal incontinence but the carer did not report that the teacher took action to directly support the student with self-care.

The carers reported that service providers refused to assist their children with personal care following incontinence. A carer described initially being called from work to attend to her child who had been incontinent at school, and then, following these instances, she reported that the school did not call her and that her child returned from school soiled. She stated:

> "…they [school personnel] used to call me at work to go to school to help him clean up [following fecal incontinence] because he said he couldn't do it himself… they've never called me since. He still does it. He'll come home smelling."

The experience described by the carer in the above quote highlights that child's fecal incontinence was associated with his impairment to be independent in self-care following incontinence.

Similarly, another carer reported that school personnel would not assist her child following incontinence. In the following quote, we asked the participant what happened when her son was incontinent at school.

> "So when there were accidents at school—
>
> They won't change him. "

One mother described her frustration and exasperation about the inactions of school staff that she observed when she arrived at school after being called to assist her child who had been incontinent. She stated:

> There were seven adults standing in the room, and he was standing there covered in poop. No one would touch him, and no one stopped him from doing it… But he's special needs. He needs you [school personnel] to have that interaction with him… You're going to have to give him that assistance. He's not a typical child. He's not going to just move when you tell him to. And they won't. They won't.

The carer outlined that her son's needs for assistance with personal care and behaviour were unique and differed from the needs of "typical" children but that school personnel would not change their approach to meet his needs. The inaction of the staff left the needs of the children unmet. Furthermore, and troubling was the carers' perception that staff were resistant to assist their children. The carers described their relationship with staff and their children's relationship with staff negatively and as oppositional.

Untouchable as a Social Consequence

From these situations, the carers described the social consequences that the child experienced or that they perceived their child would experience from peers. One carer spoke about her child's peers commenting on her child's fecal odour and reporting to school staff that her child had been incontinent. She reported:

> " Sometimes they [child's peers] say, '[child's name] stinks.' One day when the school called me [to come and assist her child to change soiled clothes]… I said, 'Who told you that he did this [that the child had been incontinent]?' And she said, 'One of the students.' "

The typical privacy maintained by children who are continent and independent with toileting and self-care regarding elimination was not afforded to the child who was incontinent and dependent on others for personal care. The child's peers ridiculed and centred him out because of his incontinence.

Another carer described the actions taken by the staff to remove the other children from the classroom, away from her child. She perceived that these actions stigmatized her child and amplified his peers' awareness that her child had been incontinent. She further speculated how this influenced how staff subsequently perceived him. She stated:

> When the whole poop thing happened they removed the class right? That happened in front of the class… Instead of stopping it they made this big spectacle, where he just kept going on. They hoarded all the other children and removed them from the classroom like it was a danger or something… I can just imagine what they [school personnel] say when they get home: 'That kid I had today, he touched his poop again.' I feel like that's what's going on.

The lack of support that the children received to either use the toilet or to clean up following incontinence undermined their dignity and privacy. The children's peers and support staff spoke negatively about and distanced themselves from the children who had been incontinent. These actions illustrated that the child was perceived as untouchable because the child was associated with feces, an attribute that repulsed others and stigmatized the child (Goffman, 1991).

Carers discussed their children's fecal incontinence as part of how they understood ID. Carers understood fecal incontinence as a challenging behaviour that was a problem to be addressed with the child and as an expression of the child's need for personal care support and to have their forms of communication understood by others. The children's privacy of fecal elimination and need for personal support in cleaning up were breached and the children's peers and school personnel separated themselves from the children with ID and made disparaging remarks to the children when they were incontinent.

Discussion

In this paper, we highlight the connections between the interconnected concepts of fecal incontinence, untouchable, and needs that emerged from the full study (Don, 2019). Carers perceived fecal incontinence as the child choosing, within their capacity to make decisions about fecal continence, to be resistant and misbehave. At the same time, carers also alternatively perceived that fecal incontinence was the consequence experienced by their child when they did not receive the supports they needed to either have successful continence or have assistance in personal care following incontinence. Within the extant literature, researchers have yet to explore fecal incontinence beyond a medical model perspective. It is unclear how the social and practical needs of children with ID may contribute to fecal incontinence. Researchers have positioned fecal incontinence both as a "normal", static, co-morbidity experienced by children with ID and as a voluntary oppositional and resistant behaviour (APA, 2013; Call et al., 2017; Niemczyk et al., 2016; Niemczyk et al., 2017). Indeed, Matson and LoVullo (2009) asserted that treatment interventions have focused primarily on medical approaches implementing pharmaceuticals and psychological approaches using behaviour modification methods. From both positions, the child with ID and fecal incontinence was located as the problem requiring change.

Diagnostic labels reinforce the stratification of children with fecal incontinence to be "reduced" to being understood according to pathophysiology and psychological criteria, while excluding the context in which they experience fecal incontinence (Kralova, 2015). In this study, we identified practical support barriers and communication practices that privileged normative development to independently be continent, toilet, and perform self-care, and normative methods of communication that disabled children with ID from having their elimination and self-care needs met within the service system. These nuanced understandings are illustrative of important ways of knowing about fecal incontinence experienced by children with ID, previously excluded from "what counts", or is recognized as being part of fecal incontinence (Holmes et al., 2008, p. 47). Powers (2001) critiqued nursing diagnoses in the same way for reducing people into certain types of patients and "stripping them of contextual, ethical, and human dimensions" (p. 21), excluding consideration of human differences, with an objective of assessing a person's deviancy and performing interventions that return them to a more normal state (p. 84). Discourse about fecal incontinence experienced by children with ID has similarities in the medicalized focus; however, there are inconsistencies regarding a child's capability to choose or simply involuntarily exhibit fecal incontinence.

Furthermore, the findings of this study illustrate nuanced aspects that contribute to fecal incontinence. According to M. Foucault (1980), identification of discursive similarities and inconsistencies undermine the assumed accuracy and comprehensiveness of diagnostics or other discourses adopted as scientific truths and locate places to critique the status quo. The stratification of children with ID and fecal incontinence as the focal problem has ramifications also on the ensued stigmatization of the child both by being visible as not having achieved normal elimination development but also by subsequently experiencing social death by not being recognized as individuals and lost opportunities to receive needed toileting and self-care supports (Goffman, 2007; Kralova, 2015).

Strengths and Weaknesses

As outlined in "Procedures", the strengths of this study include our thoroughness in outlining our methods and including ample direct quotes, researcher reflexivity, and the overall internal coherence of all aspects of the study.

The limitations of this study are that children with intellectual disability and fecal incontinence and service providers were not included. Researchers employing Foucauldian discourse analysis focus on obtaining heterogenic discourse instead of heterogenic participants to thoroughly address the research questions (Phillips & Hardy, 2002; Powers, 2001). Nonetheless, future research could include service providers and children with intellectual disability, who are often excluded from participating in research, to potentially enhance the variability of discourse.

Study Implications

This study provides nuanced insight into the challenging issue of fecal incontinence, from the perspective of carers of children with intellectual disability, who are often excluded from research about fecal incontinence. The results of this study broaden our understanding of fecal incontinence from focusing on the children with fecal incontinence as the central focus for interventions. The implications of this study may aid carers and service providers to evaluate physical and communication needs that may be disabling barriers for the child, their role and approach in supporting the child's needs with elimination, and the consequences of possible social stigma incurred by the child when fecal incontinence is viewed as inherent to their disability and their peers witness service providers' hands-off approach to supporting the child when accidents occur.

Future Research

Future research is needed to explore how service providers may better support and adapt to the unique elimination needs of children with ID to better support their ability to be continent or to address their self-care needs when incontinence occurs in a therapeutic approach. Future research could explore the effectiveness of clinicians conducting a comprehensive assessment of all of the potential factors that may be contributing to, or resulting as a function from, a child's experienced fecal incontinence and planning interventions according to the individual child's needs. Researchers could apply the framework of positive behavioural support to inform a holistic assessment, including examining the environmental for disabling barriers to the child's continence and unmet needs (Carr et al., 2002). Previous researchers have found positive behavioural support approaches to be successful in supporting persons with ID and scatolia (smearing of feces) (Martin, 2013) and coprophagia (ingestion of feces) (Baker et al., 2005) and other behavioural communications of need (Singh et al., 2020).

Health care and education providers can apply the findings of this study by collaborating with carers of children with ID to assess and determine the individual factors contributing to a child's with ID experience with fecal incontinence and developing individualized supports accordingly. Service providers should also reflect on how fecal incontinence influences their perception of children with ID and their willingness to explore potential associated needs and support children's incontinence and self-care needs.

Further policy work is also needed to explore how service workers may foster more positive and collaborative relations with carers. Additionally, service agencies serving children with ID and fecal incontinence should establish policies that promote maintaining the dignity, privacy, and provision of support of children with ID in toileting and when experiencing fecal incontinence. Additionally, educational policies should examine ways of teaching children to accept their peers with different levels of independence with toileting and self-care.

Key Messages from this Article

People with Disabilities. Children with ID often have problems learning to poop on the toilet and often need help to do this and to clean up when accidents happen. Sometimes other people may treat children with intellectual disabilities differently or step away from them if they have an accident. Service providers should try to see how services given to children with intellectual disabilities may make it hard or not be helpful for children with intellectual disabilities to poop on the toilet or clean up after.

Professionals. Fecal incontinence is a multifaceted issue. Service providers and professionals serving children with ID should explore how social and practical barriers may also contribute to the child’s experience with fecal incontinence.

Policymakers. Policies specific to services for children with ID should include recognition that fecal incontinence may be a challenge experienced by children with ID and should include provisions for supports that holistically address the unique needs of each child with ID that experiences fecal incontinence.

Messages clés de cet article

Personnes ayant une incapacité : Les enfants ayant une DI ont souvent des difficultés à apprendre à faire caca sur la toilette. Ils ont souvent besoin d'aide pour le faire et pour nettoyer en cas d'accident. Parfois, des personnes peuvent traiter les enfants ayant une déficience intellectuelle différemment ou s'éloigner d'eux s'ils ont un accident. Les prestataires de services doivent essayer de voir comment les services fournis aux enfants qui ont une DI peuvent être non-aidants ou rendre difficile pour eux de faire caca sur la toilette ou de nettoyer ensuite.

Professionnels : L'incontinence fécale est un problème à multiples facettes. Les prestataires de services et les professionnels desservant les enfants ayant une DI devraient explorer comment les obstacles sociaux et pratiques peuvent aussi contribuer à l'expérience de l'enfant vivant de l'incontinence fécale.

Décideurs : Les politiques spécifiques aux services pour les enfants ayant une DI devraient inclure la reconnaissance que l'incontinence fécale peut être un défi rencontré par les enfants ayant une DI et devraient inclure des dispositions pour des soutiens qui répondent de manière holistique aux besoins uniques de chaque enfant ayant une DI qui souffre d'incontinence fécale.

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