

Post-Disclosure of a Child's Developmental Diagnosis: Where Do We Go From Here?

Tammy Pearson, PhD, MSW, RSW

Assistant Professor/Acting Chair

School of Social Work, University of Northern British Columbia, 3333 University Way, Prince George, BC, V2N 4Z9

Corresponding author: Tammy Pearson, PhD, MSW, RSW

tammy.pearson@unbc.ca

Acknowledgement

The author sincerely thanks the parents who participated in this research study. The author would like to acknowledge the support of the Northern Health Research Review Committee and the multidisciplinary teams across northern British Columbia.

Funding: The author received no financial support for the research, authorship, and/or publication of this article.

Declaration of Conflicting Interests: The author declares that there is no conflict of interest.

Abstract

Concern for the well-being of their child typically motivates a parent to obtain a developmental diagnostic assessment. During a family meeting, the parent receives a final assessment report, including practical recommendations supporting the family and the child's developmental trajectory. Factors that influence how parents apply the recommendations have not been well identified.

This study used a qualitative method which supports the researcher's social work discipline as an effective theoretical framework. Relevant social work theories and social constructionism rooted in a subjective epistemology framed the research design – Interpretive Description. This structure provided an examination of multiple factors that influence how parents implement recommendations. Rather than pursuing a singular truth, such as one "right way" to do something, social work seeks to uncover truth claims and draw upon multiple ways of knowing to determine the best way to intervene within a particular context. A total of 17 parents participated in the study regarding their experience implementing recommendations developed by one of the multidisciplinary teams in northern British Columbia. Parents' accounts identified protective factors that support the application of the clinical recommendations and risk factors that limit the parents' ability to implement the practical interventions. Having the coordinator contact the parents after the family meeting, connecting the parents to a key worker, and sending the report prior to the scheduled family meeting were identified as protective factors. Conversely, no follow-up from a professional, the absence of a key worker, and receiving the report at the family meeting were noted as risk factors. The overarching theme was "Where do we go from here?" The sub-themes were post-disclosure, the final evaluation report, and recommendations.

Keywords: *Applied interventions; Evaluation report; Post-disclosure; Qualitative method; Recommendations*

Introduction

Approximately 16% of children experience a developmental issue during their childhood (Levy, 2011; Ogundele, 2018; WHO, 2001), and there has been a recent spike in the incidence of neurodevelopmental disorders in children resulting in emotional and behavioural problems (Blanchard et al., 2006; Brauner & Stephens, 2006; Fombonne, 2009). Given the complex clinical features associated with various neurodevelopmental disorders, a child's comprehensive diagnosis is best served by the breadth of expertise on a multidisciplinary team (Fazel et al., 2021; Hudson, 2014; Lamb et al., 2014; Nicholas, 2020; Strunk et al., 2017). Multidisciplinary teams usually include developmental pediatricians, psychologists, speech-language pathologists, occupational therapists, and social workers, all of whom aid in the delivery of the diagnosis (Klein et al., 2011).

Many parents of children with disabilities sought a diagnosis because an assessment of their child's symptoms would induce an intervention plan which would prompt an enriched life for both the child and the family (Gillman et al., 2000; Shevell & Shevell, 2013). Generally, the child is assessed individually by several professionals on the multidisciplinary team to obtain the most comprehensive assessment with effective and sound recommendations. In essence, the overall purpose of the diagnostic process is to allow the development of tangible recommendations to enhance the lives of the individuals in question, their families, and their community (Chudley et al., 2005).

The impact of healthcare professionals' style of communication on patients has been studied in various healthcare capacities, and the quality of the interaction has proven to be a positive link with an individual's ability to follow through with treatment recommendations (Charon et al., 1994; Singh et al., 2008; Stewart, 1995). As such, parental satisfaction is a vital component in the execution of their child's treatment plan and future well-being (Bartolo, 2002). Similarly, studies conducted in medical environments have demonstrated that satisfied patients are more likely to engage in the medical diagnostic process, achieve higher levels of compliance with treatment recommendations, experience improved signs of ailment control, and act in a manner that ultimately leads to positive outcomes for the mental and physical health of the patient and the family (DiMatteo et al., 2012; Doyle et al., 2013; Hall et al., 1993; Irish et al., 1995; McLaughlin, 2005; Price et al., 2014; Roter et al., 2002). In other words, the quality of the interaction is a positive link to the individual's ability to follow through with treatment plans and recommendations (Charon et al., 1994; Singh et al., 2008).

Likewise, how a child's disability diagnosis is delivered can significantly affect the parents' ability to follow through with clinical recommendations (Ahmed et al., 2013). Larson et al. (2017) stated that unsatisfactory communication between healthcare professionals and patients fosters non-compliance. Pearson et al. (2020) identified that a parent's perception of a power imbalance deterred them from asking questions during the clinical interaction.

The seating arrangement, coupled with professional attire, created a sense of division between the professionals and the family, which unintentionally hindered parental communication. Research from various professional disciplines, in particular social work, identifies effective practice methods clinicians can employ during a clinical encounter that strategically dismantle power imbalances when communicating with individuals and families (Jupp, 2005). Furthermore, healthcare professionals' use of medical jargon was noted as a limitation in fostering successful communication (Latibjonovna, 2021). It is important for all health practitioners to adhere to a best practices guideline in keeping with the notion of universal precaution when communicating medical information with families. For example, healthcare personnel approach disease control by wearing proper medical gear – whether or not a particular individual may be contagious. Likewise, clinicians on the clinical teams should impart diagnostic information in lay terms to all parents regardless of their apparent level of health literacy.

In addition, a significant delay in receiving a child's developmental diagnosis negatively influences parents' adherence to treatment recommendations. For example, Webb et al. (2014) reported that delays in receiving a diagnosis could hinder the implementation of effective support and appropriate intervention strategies. Parents described the involvement of supports post-diagnosis as unsatisfactory and as an area of concern (Crane et al., 2015). Several researchers examined various perspectives during and after the comprehensive diagnostic assessment process. However, very little has been published on the determinants of parental understanding and the influence this has on parents' ability to implement clinical recommendations. This poses a concern given that parental adherence to clinical recommendations is crucial to positive outcomes for children (Ferguson et al., 2021; Hock et al., 2015; Rovane et al., 2020; Yingling et al., 2018). This apparent gap in clinical practice knowledge provided the foundational rationale for this study.

In this study, the northern multidisciplinary teams comprise the following professionals: a pediatrician, a psychologist, a speech-language pathologist, and an occupational therapist (Northern Health, n.d.). The teams are situated within a larger healthcare system that serves residents across northern British Columbia. Depending on funding and contract services with local agencies, some families were connected to a key worker (support worker) who provided services to families of children and youth with complex developmental behavioural conditions. The Key Worker Program is funded by the Province of British Columbia to provide support to families with children and youth under the age of 19 who may have a complex behavioural disorder. Key workers have varied academic credentials, which may include a Bachelor of Social Work or Education (Special Education) and Counselling Psychology. The program has an open referral process, including referrals from parents, caregivers, physicians, and other community supports.

Upon completion of the comprehensive assessment, the multidisciplinary team met with the family to explain the results (the family meeting). After the family meeting, the family received a written final evaluation report highlighting their child's diagnosis and recommended interventions unique to their child. This study identified factors that influenced how the clinical recommendations were implemented following the delivery of the diagnosis.

Methods

This study used a qualitative method known as interpretive description, conceived, and derived from the discipline of nursing. This method borrows the best techniques from conventional social sciences in the absence of external theoretical constraints. In essence, it accepts the theoretical and practical knowledge a researcher brings to their research and assumes that the researcher is affiliated with an applied discipline (Thorne, 2008; Thorne et al., 1997). Drawing upon social work theory (a broad and diverse range of sources known as eclecticism), knowledge, and practice to structure the research required a methodology that provided opportunities for description, interpretation, and pragmatic action (Thorne, 2008). Reliance on social work's disciplinary epistemology, influenced by social constructionism, and tacit knowledge framed this applied research study. Epistemology is simply "the theory of knowledge" (Willis, 2007, p. 10). Who knows more about a situation than the person experiencing the reality? A guiding social work principle supports this question – "the social worker should consider clients as experts in their own life" (Sheafor & Horejsi, 2014, p. 53). Social constructionism allows research to proceed with the assumption that reality is socially constructed, which gives value to the context in which the individual makes sense of their world (Creswell, 2003). Transferring tacit knowledge obtained in one context (child welfare) to a different environment (healthcare clinical setting) to inform practice (Fook et al., 2000) contributed to this study. The researcher witnessed families' confusion when a child protection worker provided a written family plan outlining recommendations to mitigate risk. Within this tangled web of experiences, family plans were not implemented, resulting in poor outcomes for the children and families.

Eligibility criteria

The following eligibility criteria were developed: the parent may be the birth parent or the parents of an adopted-at-birth child or youth under the age of 19 the team had previously assessed; must have an open file with the multidisciplinary team (post-assessment for a period of four to six weeks until the parent received the report); and must be a resident of northern British Columbia. The clinical teams are situated within a larger healthcare system that serves residents across the northern part of British Columbia, Canada. Northern British Columbia covers a large geographical area encompassing many rural areas, which include families from diverse cultures. Seventeen participants met the criteria for participation. The participants varied in income, education, employment, gender, status, and race.

Participants and recruitment

Following approval from two review ethics boards, a purposive sampling strategy was used to recruit parents of children who had received a developmental diagnosis from one of the multidisciplinary clinical teams. A gatekeeper (clinical coordinator) assisted with the recruitment process by contacting families post-assessment during routine clinical follow-up calls and informing the parents about the research study. Following their verbal approval, the researcher received contact information for 14 families interested in participating. The researcher intended to recruit a sample of approximately 20 participants, a number contingent on whether redundancy was reached.

At this point, the researcher implemented a snowball sampling recruitment process to identify additional participants, given the sample size was below the intended target range. Snowball sampling identifies prospective participants through their connections to known individuals, such as colleagues, friends, and acquaintances who understand the research goals and can make recommendations based on their knowledge regarding the eligibility of potential subjects (Patton, 2002). In this case, the researcher solicited the assistance of a colleague who identified three participants that met the eligibility criteria and agreed to participate in the study.

Interview procedures

The researcher utilized a semi-structured interview guide equipped with only open-ended questions. A semi-structured interview format enables the participant to freely express their unique views in their own language (Olson, 2011). The 17 interviews took place within two months in the spring of 2015. The participants requested to have their interviews in various settings. Nine occurred in an organisation's office, and the remaining eight were at the participant's residence. Follow-up conversations were held with 10 of the 17 participants to clarify information associated with the data and for member checking. The researcher audio-recorded, transcribed and analysed all the interviews. Seventeen parents volunteered to participate in this research study. Thirteen of the participants were female: seven were the biological mothers of the children, and six were adoptive mothers. Four of my participants were male: two were the biological fathers of the children, and two were adoptive fathers. The participants were diverse with respect to income, education, employment, gender, status, and race. Much of the demographic information was garnered by speaking directly to the participants rather than by way of a questionnaire. As a result, education level and employment information are not reported.

Data analysis

The author generated findings using thematic analysis as developed by Braun and Clarke's (2006) six-step approach. To identify the patterns that captured the parents' experiences, the researcher identified answers that aligned with the research question. Once 17 interviews were conducted and analysed, no new themes emerged from the data, which denoted the point of saturation (Denzin & Lincoln, 2011). The overarching theme became evident, and sub-themes were developed to account for subtleties and differences from the theme capturing the foundation of the parents' commonalities, patterns, and connections.

Results

Receiving a child's developmental diagnosis was an important turning point in what several participants described as a "long journey". For some, it was important to have a name for what they observed in their child's behaviour. Many reported mixed feelings. How to proceed regarding their child's developmental trajectory was on their mind. The participants reported feeling ambivalent about the next steps involved in supporting their child's progress through there commended interventions. Much of their uncertainty concerned addressing the recommendations and how they would decipher the clinical content in the final evaluation report.

The parents' diverse views were grouped into three sub-themes (post-disclosure, the final evaluation report, and recommendations) derived from one overarching theme, "Where do we go from here?" Sub-themes are illustrated by quotations taken from participant interviews. Each participant was assigned a pseudonym to maintain their anonymity.

Overarching theme: Where do we go from here?

Sub-theme 1: Post-disclosure

Several participants were concerned by the lack of opportunity to meet with the multidisciplinary team following the formal diagnostic process. Essentially, participants wanted another chance to ask follow-up questions after the delivery of their child's diagnosis. They wanted to fill the gaps in their understanding of the diagnosis and the recommendations. They described being left to digest the diagnosis and the recommendations in the absence of professional contact. For example, Ellen had no contact with the multidisciplinary team after receiving her son's diagnosis and felt her understanding diminished over time. She said:

The opportunity for follow-up down the road would be really good. After the meeting, we came away, we had the recommendation, we had this understanding, and then that definitely had decreased over time. If someone would have checked in with us three months later to see if we are doing anything, if we read the report, if we had any questions, that probably would have been good.

Kate shared her thoughts:

It is a little overwhelming to have it all and then to have no opportunity for questions after. Another meeting maybe after you get the full report because it was nice for them to go over the summary with us.

Ashley was excited that she received a call from the clinical coordinator informing her about this research opportunity, but she questioned the timing of the call. Ashley recalled:

I think having someone reach out, even just getting this call from the coordinator, when she called, and I was, like, that's wonderful to feel like somebody was checking in . . . that's what she said, "I'm just calling to check in and follow up." I said, "Wow, I'm so happy you called because, some questions have come up," and so she was able to say, "Yes, there is this key worker who can kind of go through this with you and fill in those blanks." Get somebody to call and check in sooner, right? So, the family meeting was in November. It's now March, so they could've even got her to call earlier.

This was a common reaction, where parents felt the need for another opportunity to ask questions about the diagnostic findings and recommendations. Allowing parents to develop their comprehension post-disclosure and return later to discuss outstanding questions was crucial for them to move forward.

Sub-theme 2: The final evaluation report

The multidisciplinary team completed a comprehensive final report as part of the child's diagnostic assessment and evaluation process. Many of the families were also given a summary report before or at the conclusion of the formal diagnostic process. The team mailed the final evaluation report to the parents. It included recommendations to maximize the child's full potential for development, including information on support services and other interventions. Parents talked about the quality of the report and discussed whether and to what extent they thought it was understandable, accurate, and informative.

Alley said she benefited from having read the summary in advance because such preparation helped her to understand her child's diagnosis and, more importantly, it allowed her to formulate questions ahead of time:

I just had the summary prior to the family meeting, but just to be able to ask questions for clarification, it was a lot easier to understand. Explaining in layman's terms the technological pieces that were done . . . it was very helpful bringing it down to words that I could understand.

In contrast, Arlene did not receive the summary prior to the family meeting, which she found frustrating. She explained:

They gave me the paperwork. We went over it briefly in the meeting, and they asked if I had any questions. It would've been nice if I'd been supplied the information ahead of time. Then I would've had time to look over it and be prepared with questions.

Some of the parents found the final report too complex, which compromised their ability to understand the diagnostic findings and recommendations. Some required assistance when it came to interpreting much of the information. Kate explained the report in this manner:

When you get the report, some of the information, it's really not in layman's terms. So, you find you're Googling, or trying to kind of figure stuff out . . . when you're reading the information. . . . They used big language in the final report, but with the Internet we kind of tried to piece things together trying to relate the information to how he behaves. Maybe some interpretation of the report might be beneficial, like, I don't know what cognitive behaviour is.

The participants' observations regarding the content of the final report highlighted the importance of a professional standard of documentation in a clinical report – accurate records reflect credibility. For example, Rita was concerned about demographic inaccuracies in the information recorded for her family, which made her wonder about the report's credibility. Rita explained, “the report that was received from the team has errors regarding my daughter's ethnicity and the gender of her sibling.”

Likewise, Arlene reported that “aspects of the report were inappropriate and unnecessary and [it] was more about personal opinion” – an emphasis on her daughter’s weight, which Arlene thought could have impacted her daughter negatively if she had chosen to read the report (she did not).

Finally, some parent participants found the report informative and expressed gratitude when reading about their child’s circumstances. For example, Tina enjoyed reading the report and found it very useful – she referred to it in terms of a diary that included a thorough historical picture which gave her an opportunity to reflect on her journey as a mother:

The report was very clear, concise. Every person involved did a historical piece. So, from the beginning, it flowed completely to the day of the assessment. It was just super thorough. It provided a lot of professionals’ perspectives and their knowledge, and it was very clear and concise and very positive.

Similarly, Cathy appreciated the clarity of the report and noted that it included additional information not covered at the meeting: “When I got the report too, it even had more information in it than what was at the meeting, and a lot of resources.” As observed in this study, good quality reports were necessary for the competent delivery of clinical services and interventions.

Sub-theme 3: Recommendations

The experiences of the parent participants varied when it came to dealing with the recommendations. During their interviews, the parents talked about the significance of the recommendations developed for their child and how they could incorporate them in home and school settings. Fourteen of the 17 participants specifically addressed the recommendations; of these, eight felt relatively well-advised and satisfied, and six felt they needed more guidance and information.

Cathy indicated that she successfully implemented all the recommendations because she had the assistance of a key worker. She noted:

All of the recommendations were implemented. That had a lot to do, too, with the key worker because she went to the school with me afterwards and met with everybody and explained what needed to happen and what she needed.

Frank made similar comments:

I was coached through a lot of it by the key worker, which is great. She did a lot of explaining. She really could pick up on a lot of different things where I can’t as clearly, and so she would cut in sometimes and break it down a little further when she felt that it was needed for me. I think not having her there would’ve been probably a little more nerve-wracking but having her there was great. She helped me with the recommendations.

Alley also felt the recommendations were helpful and well-outlined, and being able to bring them into the school setting made a “significant difference” to her son’s behaviour. As she explained:

It was very helpful, and it was outlined such as “step one, do this.” They gave me online resources, and I’m pretty computer savvy and . . . able to self-help and be an advocate for yourself to seek out further steps and stuff that was super helpful. There’s a challenge with being out of the main centres in the province, right, to be able to access more support, but we’ve implemented almost all when it comes to the school system. Since the implementation of the recommendations there has been significant difference with my son, like night and day.

On the other hand, Betty wanted more information regarding her son’s diagnosis but appreciated that her education enabled her to do her own research. She realized this might not be the case for everyone. She said:

More information on my child’s diagnosis. I wasn’t given any of that. I’ve done my own research, and I’ve read quite a few books prior to having the suspicion. But let’s just say if I wasn’t as high functioning, I would think that might be a difficult thing if you were given a diagnosis without any sort of resource material. That’s the first thing you say, “Okay, what do I do, where do I go, what’s next? How do I treat this person now that I know this?” More tangible, physical resources available then and there to say, here’s some information. So, I took the initiative, made the family doctor appointment and said, after much research on my part, you know, “I’m willing to go forward on this, here’s his diagnosis, it’s ADHD, what do you recommend?”

Similarly, Lisa felt that the report fell short when it came to making practical and helpful recommendations. It essentially told her what she already knew – that her child needed external support services – but she wanted more information.

There weren’t really any recommendations. It was just that one sentence stating that mother needs extensive support services and that was it. I ended up having to go to my counsellor saying, “What do I do? Like, where do I go?” They’re saying I need extensive support services. I know I do. In order to help my child’s behaviours, I need some support, but there was no follow-up on that or “Do you have any questions about what we can do for you?” [or] any services and stuff like that. They just basically said you need that full report.

Discussion

This study focused on parents’ journey regarding implementing the clinical recommendations outlined in the final evaluation report provided by one of the multidisciplinary teams in northern British Columbia. The study generated protective factors that supported the parents in applying the clinical recommendations and risk factors that limited their ability to implement the interventions.

Although it is not appropriate to form generalisations from the data in this study, this important research allows for the generation of new ideas. It can inform clinical practice and create innovative practice techniques for the delivery of diagnostic findings and recommendations which, in turn, may improve outcomes for children and families. Many of the parents expressed a strong desire for follow-up after the family meeting to ask questions regarding their child's diagnosis and clarify information about the team's clinical recommendations.

Unfortunately, the parents in this study did not have an opportunity to meet with the multidisciplinary team post-disclosure. They reported that the lack of follow-up was a risk factor. It is important to note that, despite best efforts to take precautions when imparting information about the diagnosis and recommendations, the process happens very quickly. The practitioners involved do not have the time for a follow-up appointment or repeated visits with the family (Nissenbaum et al., 2002). It is not surprising that post-diagnostic support was an area of concern, as comparable studies indicate a similar experience following the disclosure of a developmental diagnosis (Crane et al., 2015; Jones et al., 2014; Mansell & Morris, 2004). In the study conducted by Crane et al. (2015) in the United Kingdom, only 21% of parents received a direct offer of assistance, 38% were marked for follow-up, and 35% revealed no assistance subsequent to the diagnostic process.

Furthermore, some research findings indicate the value of a follow-up meeting shortly after the diagnosis and emphasise the importance of the presence of the same professionals who provided the diagnosis to the family (Kisler & McConachie, 2010; Sloper & Turner, 1993). This study noted that a few parents received a call from the clinical coordinator shortly after "the final meeting, which was a protective factor. Therefore, having the clinical coordinator follow up with all parents shortly after the family meeting to verify the linking of the family to the appropriate community resources was well accepted.

Several parents in this study had a key worker, which proved to be a protective factor with the management of the recommendations. The key worker was instrumental in creating the shift from the clinical diagnostic team to the various wraparound services in the community where the clinical recommendations were applied. They informed the parents about local community services and, in some cases, improved communication between various systems – the child's school personnel, allied healthcare professionals, community agencies, and the parents. This finding concurs with a study by Sloper and Turner (1993), where 103 families of young children with a disability identified the positive contribution of a key worker when families are required to navigate several service delivery areas. In 2020, research findings reiterated the value of professional support before and after a child's developmental diagnosis (Fisher et al., 2020).

Unfortunately, not all parents in this study were assigned a key worker. The inconsistency resulted from budget cutbacks and funding issues with the provincial government at the time of this study, which, in turn, affected vulnerable children and families. Walz et al. (2019) highlighted parents' frustration when their child's needs were unmet due to budget and funding issues resulting in the demise of support services. As a result, a few risk factors identified, such as underfunding of services and maldistribution of resources (key workers), are beyond the scope of the clinical teams.

That said, changing the model of the team by one additional clinician – in particular, a registered clinical social worker – whose primary role is to mitigate the risk factors would enhance the health outcomes for the child and the family. In fact, most multidisciplinary clinical teams include a social worker to address the essential services that the family requires (Klein et al., 2011; Min et al., 2016). In this study, a social worker was not a part of the multidisciplinary team, but the need for this professional role was identified. A social worker with a Master of Social Work degree can play an integral role throughout the various stages of the clinical diagnostic trajectory. They can attend to the parental knowledge gaps related to the diagnosis, the emotional health of the parent(s), and the delivery of the diagnosis. A study by Min et al. (2016) used social workers to evaluate medical students' delivery of bad news during patient encounters. The results highlighted that the medical students valued social workers' expertise in delivering bad news.

Similarly, in several other studies, parents experienced a cascade of emotions upon hearing their child's disability diagnosis, which jeopardized their interpretation of the information being delivered (Bartolo, 2002; Pearson et al., 2020; Shevell & Shevell, 2013). These findings validate the need for a social worker on a multidisciplinary team because of their knowledge and skills to cover a broad range of complex situations. When parents learn about their child's developmental diagnosis, it impacts their emotional health, and they often experience the various stages of grief (Bartolo, 2002; Pearson et al., 2020). Social workers are equipped to manage clients' emotions with the highest level of professionalism, which can be an asset for the parent's well-being.

The parents had mixed experiences in relation to the final evaluation report. Some received a summary report of their child's diagnosis before the family meeting and reported a positive experience. They had the opportunity to read the summary report and prepare questions before the meeting, making the final report much easier to understand. Parents deemed the clinical practice of mailing out the summary report before the final family meeting a protective factor. Clinical teams in various parts of the northern region of British Columbia are providing this service. In contrast, the parents who faced difficulty comprehending the final report were not connected to a key worker and did not receive the summary in advance. This study finds that sending the summary report to the parents at least a week before the final meeting will not only improve the parental understanding of their child's diagnosis but also assist the parent with implementing the clinical recommendations. In keeping with such findings, Klein et al. (2011) found that when parents are given a summary report outlining the diagnosis following the diagnostic disclosure session or the final meeting with the health practitioner, they are not yet prepared to act upon written instructions. At the same time, Cranwell and Miller (1987) pointed out that "it may be too great a task for any one document to provide information to give indications of appropriate teaching approaches, techniques and materials, and to present a comprehensive picture to parents" (p. 27). Wickerd and Tremblay (2021) questioned the validity of adaptive rating scales that are given to parents when a child may have a developmental disability. The rating form depends entirely on the parent's ability to read and comprehend the written instructions. Another study reported that parents could have difficulty comprehending written materials pertaining to their child's developmental evaluation (Fitzgerald & Watkins, 2006), reinforcing the need for a social worker to be a member of the multidisciplinary team.

Limitations

This study has limitations that should be kept in mind when considering the findings. Although qualitative research does not require large sample sizes and saturation was reached – suggesting that the sample size was sufficient given that the scope of the research was limited to the recommendation in the final evaluation report – the sample size was small. Additionally, most parents received their child’s diagnosis from a multidisciplinary team in a northern urban centre, and it was difficult to get a sense of the regional variation in clinical practices. In future research, a sample that includes an equal number of parents serviced by the various clinical teams could generate best clinical practice guidelines for northern British Columbia. In addition, a larger sample size with greater cultural diversity would further strengthen the dataset.

Conclusion

This study shed light on the factors impacting parents’ ability to implement recommendations outlined in the final evaluation report. The study recommends several protective factors in clinical team practice, manifesting positive outcomes that make a difference to the families they serve. A truly integrated diagnostic process would include the clinical assessment, the final family meeting, and a social worker who bridges the family to community resources and aids with the comprehension of the final evaluation report. The health and social services systems need to engage in an in-depth conversation and create a shared vision for children with developmental disabilities, bridging the diagnostic assessment/clinical recommendations to the helping professionals employed in the various community resources. Is there value in a developmental assessment if the recommendations are not implemented due to systemic issues? Directing and guiding parents in the right direction after the disclosure of the diagnosis is paramount to the child’s best interest.

Acknowledgements

The author sincerely thanks the parents who participated in this study. The author would like to acknowledge the support of the Northern Health Research Review Committee and the multidisciplinary teams located in northern British Columbia.

References

- Ahmed, R., McCaffery, K. J., & Aslani, P. (2013). Factors influencing parental decision making about stimulant treatment for attention-deficit/hyperactivity disorder. *Journal of Child and Adolescent Psychopharmacology*, *23*, 163–178.
- Bartolo, P. A. (2002). Communicating a diagnosis of developmental disability to parents: Multiprofessional negotiation frameworks. *Child: Care, Health & Development*, *28*, 65–71.
- Blanchard, L. T., Gurka, M. J., & Blackman, J. A. (2006). Emotional, developmental, and behavioral health of American children and their families: A report from the 2003 National Survey of Children's Health. *Pediatrics*, *117*, 1202–1212.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77–101.
- Brauner, C. B., & Stephens, C. B. (2006). Estimating the prevalence of early childhood serious emotional/behavioral disorders: Challenges and recommendations. *Public Health Reports*, *121*, 303–310.
- Charon, R., Greene, M. G., & Adelman, R. D. (1994). Multi-dimensional interaction analysis: A collaborative approach to the study of medical discourse. *Social Science & Medicine*, *39*, 955–965.
- Chudley, A. E., Conry, J., Cook, J. L., Looock, C., Rosales, T., LeBlanc, N., & Public Health Agency of Canada National Advisory Committee on Fetal Alcohol Spectrum Disorder. (2005). Fetal alcohol spectrum disorder: Canadian guidelines for diagnosis. *Canadian Medical Association Journal/Journal De L'Association Medicale Canadienne*, *172*, S1–S21.
- Crane, L., Chester, J. W., Goddard, L., Henry, L. A., & Hill, E. (2015). Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom. *Autism: The International Journal of Research*, *20*, 153–162.
- Cranwell, D., & Miller, A. (1987). Do parents understand professionals' terminology in statements of special educational need? *Educational Psychology in Practice*, *3*, 27–32.
- Creswell, J. W. (2003). *Research design: Qualitative, quantitative, and mixed methods approaches* (2nd ed.). Sage.
- Denzin, N. K., & Lincoln, Y. S. (2011). *Handbook of qualitative research* (4th ed.). Sage.
- DiMatteo, M. R., Haskard-Zolnierok, K. B., & Martin, L. R. (2012). Improving patient adherence: A three-factor model to guide practice. *Health Psychology Review*, *6*, 74–91.
- Doyle, C., Lennox, L., & Bell, D. (2013). A systematic review of evidence on the links between patient experience and clinical safety and effectiveness. *British Medical Journal Open*, *3*, e001570, 1–18
- Fazel, M., Townsend, A., Stewart, H., Pao, M., Paz, I., Walker, J., Sawyer, S. M., & Sharpe, M. (2021). Integrated care to address child and adolescent health in the 21st century: A clinical review. *JCPP Advances*, *1*(4), e12045.
- Ferguson, E. F., Jimenez-Muñoz, M., Feerst, H., & Vernon, T. W. (2021). Predictors of satisfaction with autism treatment services during COVID-19. *Journal of Autism and Developmental Disorders*. <https://doi.org/10.1007/s10803-021-05232-0>
- Fisher, W. W., Luczynski, K. C., Blowers, A. P., Vosters, M. E., Pisman, M. D., Craig, A. R., Hood, S. A., Machado, M. A., Lesser, A. D., & Piazza, C. C. (2020). A randomized clinical trial of a virtual-training program for teaching applied-behavior-analysis skills to parents of children with autism spectrum disorder. *Journal of Applied Behavior Analysis*, *53*(4), 1856–1875.
- Fitzgerald, J. L., & Watkins, M. W. (2006). Parents' rights in special education: The readability of procedural safeguards. *Exceptional Children*, *72*(4), 497–510.
- Fombonne, E. (2009). Epidemiology of pervasive developmental disorders. *Pediatric Research*, *65*(6), 591–598.
- Fook, J., Ryan, M., & Hawkins, L. (2000). *Developing professional knowledge and competence for working in uncertainty*. Falmer Press.
- Gillman, M., Heyman, B., & Swain, J. (2000). What's in a name? The implications of diagnosis for people with learning difficulties and their family carers. *Disability & Society*, *15*, 389–409.
- Hall, J. A., Milburn, M. A., & Epstein, A. M. (1993). A causal model of health status and satisfaction with medical care. *Medical Care*, *31*(1), 84–94.
- Hock, R., Kinsman, A., & Ortaglia, A. (2015). Examining treatment adherence among parents of children with autism spectrum disorder. *Disability and Health Journal*, *8*, 407–413.
- Hudson, J. P. (2014). *A practical guide to congenital developmental disorders and learning difficulties*. Routledge.

- Irish, J. T., & Hall, J. A. (1995). Interruptive patterns in medical visits: The effects of role, status and gender. *Social Science & Medicine*, *41*, 873–881.
- Jones, L., Goddard, L., Hill, E. L., Henry, L. A., & Crane, L. (2014). Experiences of receiving a diagnosis of autism spectrum disorder: A survey of adults in the United Kingdom. *Journal of Autism and Developmental Disorders*, *44*, 3033–3044.
- Jupp, V. (2005). Issues of power in social work practice in mental health services for people from Black and minority ethnic groups. *Critical Social Work*, *6*(1). <http://web4.uwindsor.ca/units/socialwork/critical.nsf/8c20dad9f1c4be3a85256d6e006d1089/48678d37f30a9a2685256fd70066bc9f>
- Kisler, J., & McConachie, H. (2010). Parental reaction to disability. *Paediatrics and Child Health*, *20*, 309–314.
- Klein, S., Wynn, K., Ray, L., Demeretz, L., LaBerge, P., Pei, J., & Pierre, C. S. (2011). Information sharing during diagnostic assessments: What is relevant for parents? *Physical & Occupational Therapy in Pediatrics*, *31*, 120–132.
- Lamb, B. W., Jalil, R. T., Shah, S., Brown, K., Allchorne, P., Vincent, C., & Sevdalis, N. (2014). Cancer patients' perspectives on multidisciplinary team working: An exploratory focus group study. *Urologic Nursing*, *34*(2), 83–91.
- Larson, E., Leslie, H. H., & Kruk, M. E. (2017). The determinants and outcomes of good provider communication: A cross-sectional study in seven African countries. *British Medical Journal Open*, *7*(6), e014888.
- Latibjonovna, B. G. (2021). Ethics of the relationship between the medical professional and the patient system. *International Journal of Development and Public Policy*, *1*(4), 115–120.
- Levy, Y. (2011). Developmental delay revisited. *Developmental Disabilities Research Reviews*, *17*, 180–184.
- Mansell, W., & Morris, K. (2004). A survey of parents' reactions to the diagnosis of an autistic spectrum disorder by a local service access to information and use of services. *Autism*, *8*, 387–407.
- McLaughlin, J. (2005). Exploring diagnostic processes: Social science perspectives. *Archives of Disease in Childhood*, *90*, 284–287.
- Min, A., Spear-Ellinwood, K., Berman, M., Nisson, P., & Rhodes, S. (2016). Social worker assessment of bad news delivery by emergency medicine residents: A novel direct- observation milestone assessment. *Internal and Emergency Medicine*, *11*(6), 843–852.
- Nicholas, J. (2020). Cognitive assessment of children who are deafblind: Perspectives and suggestions for assessments. *Frontiers in Psychology*, *11*, 571358.
- Nissenbaum, M. S., Tollefson, N., & Reese, R. M. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities*, *17*, 30–43.
- Northern Health. (n.d.). *Complex developmental behavioural conditions* (CDBC). <http://www.northernhealth.ca/YourHealth/PublicHealth/NorthernHealthAssessmentNetwork/ComplexDevelopmentalBehaviouralConditions.aspx>
- Olson, K. (2011). *Essentials of qualitative interviewing*. Left Coast Press.
- Ogundele, M. O. (2018). Behavioural and emotional disorders in childhood: A brief overview for paediatricians. *World Journal of Clinical Pediatrics*, *7*(1), 9–26.
- Patton, M. Q. (2002). *Qualitative research and evaluation methods* (3rd ed.). Sage.
- Pearson, T., Wagner, S., & Schmidt, G. (2020). Parental perspective: Factors that played a role in facilitating or impeding the parents' understanding of their child's developmental diagnostic assessment. *Child: Care, Health and Development*, *46*(3), 320–326.
- Price, R. A., Elliott, M. N., Zaslavsky, A. M., Hays, R. D., Lehrman, W. G., Rybowski, L., & Cleary, P. D. (2014). Examining the role of patient experience surveys in measuring health care quality. *Medical Care Research and Review*, *71*, 522–554.
- Roter, D. L., Hall, J. A., & Aoki, Y. (2002). Physician gender effects in medical communication: A meta-analytic review. *Journal of the American Medical Association*, *288*, 756–764.
- Rovane, A. K., Hock, R. M., & January, S. A. A. (2020). Adherence to behavioral treatments and parent stress in families of children with ASD. *Research in Autism Spectrum Disorders*, *77*, 101609.
- Sheafor, B. W., & Horejsi, C. R. (2012). *Techniques and guidelines for social work practice* (9th ed.). Allyn & Bacon.
- Shevell, A. H., & Shevell, M. (2013). Doing the “talk”: Disclosure of a diagnosis of cerebral palsy. *Journal of Child Neurology*, *28*, 230–235.

- Singh, H., Naik, A. D., Rao, R., & Petersen, L. A. (2008). Reducing diagnostic errors through effective communication: Harnessing the power of information technology. *Journal of General Internal Medicine*, 23, 489–494.
- Sloper, P., & Turner, S. (1993). Determinants of parental satisfaction with disclosure of disability. *Developmental Medicine and Child Neurology*, 35, 816–825.
- Stewart, M. A. (1995). Effective physician-patient communication and health outcomes: A review. *Canadian Medical Association Journal/Journal de l'association medicale canadienne*, 152(9), 1423–1433.
- Strunk, J., Leisen, M., & Schubert, C. (2017). Using a multidisciplinary approach with children diagnosed with autism spectrum disorder. *Journal of Interprofessional Education & Practice*, 8, 60–68.
- Thorne, S. (2008). *Interpretive description*. Left Coast Press.
- Thorne, S., Kirkham, S. R., & MacDonald-Emes, J. (1997). Focus on qualitative methods. Interpretive description: A noncategorical qualitative alternative for developing nursing knowledge. *Research in Nursing & Health*, 20, 169–177.
- Walz, A., Wang, M., & Bianchini, J. (2019). Parental perspectives on successful parent education and behavioral intervention. *International Journal of Developmental Disabilities*, 65, 359–367.
- Webb, S. J., Jones, E., Kelly, J., & Dawson, G. (2014). The motivation for very early intervention for infants at high risk for autism spectrum disorders. *International Journal of Speech and Language Pathology*, 16, 36–42.
- Wickerd, G., & Tremblay, S. (2021). Readability of English and Spanish forms of two adaptive behavior rating scales. *Psychology in the Schools*, 58(5), 935–950.
- Willis, J. W. (2007). *Foundations of qualitative research: Interpretive and critical approaches*. Sage.
- World Health Organization (WHO). (2001). *Report 2001: Mental health: New understanding New Hope*. <https://apps.who.int/iris/handle/10665/42390>
- Yingling, M. E., Hock, R. M., Cohen, A. P., & McCaslin, E. M. (2018). Parent perceived challenges to treatment utilization in a publicly funded early intensive behavioral intervention program for children with autism spectrum disorder. *International Journal of Developmental Disabilities*, 64(4–5), 271–281.