Understanding parental concerns related to their child's development and factors influencing their decisions to seek help from health care professionals: Results of a qualitative study

Abstract

Background: Early identification of children at risk of developmental delay is crucial to promote healthy development. Assessing parental concerns about development is often part of identification processes. However, we currently do not understand well how and why parents become concerned, and, how and why they access early identification and intervention services. The purpose of this study was to explore parental perceptions about their child's development, and the factors influencing their reported professional help-seeking behaviours.

Methods: This exploratory study was part of a larger study describing child development in children aged 2-5 in a small Canadian city. We conducted semi-structured interviews with 16 parents whose children were at risk of developmental delay to examine their perceptions of their child's development, their use of community services promoting development, and their recommendations to optimize those services.

Results: Four themes were identified: 1) Vision of child development influencing help-seeking behaviours: Natural or Supported?, 2) Internal and external sources contributing to parents' level of developmental concern, 3) Using internal resources and struggling to access external resources, and 4) Satisfaction with services accessed and recommendations to access more support. Parents' vision of child development along with sources of parental concern appeared to influence the level of concern, enhancing our understanding of how parents become concerned. The level of concern, and parents' knowledge and perceived access to resources seemed to influence their decision whether or not to consult health care professionals. Parents provided many suggestions to improve services to promote child development and support families.

Discussion: Results highlight the importance of supporting parents in recognizing if their child is at risk of delay, and increasing awareness of available resources. It appears particularly important

to ensure health care professionals and community-based support services are accessible to provide parents with the support they need, especially when they have concerns.

1 INTRODUCTION

A child's early years are among the most crucial for promoting healthy development (Irwin, Siddiqui, & Hertzman, 2007). When there is a delay in one or more developmental area such as a child's physical and/or motor development, their behaviour, emotions, cognition, communication skills, or socialization, the risk of potential educational difficulties and health concerns in later life increases significantly (Desrosiers & Tétrault, 2012; Irwin et al., 2007; Paquette, 2016). It is estimated that appropximately 1 in every 5 children presents such developmental delays, with a higher prevalence of delay for children from low income families (Porterfield & McBride, 2007; WHO, 2018).

Many researchers stress the importance of early detection and referral of children experiencing difficulties and who are in need of early intervention to rehabilitation professionals for management of their difficulties and prevention of long-term sequelae (Ertem & WHO, 2012; Tang et al., 2011). It is generally accepted that parents know their children best, that they are reliable informants, and that they have a key role to play in the identification process (Glascoe, 1997, 2003). However, there can occasionally be a mismatch between children demonstrating delays and the level of parental concern about potential delays (Glascoe, 2003; Reijneveld, de Meer, Wiefferink, & Crone, 2008). Similarly, families might decide not to participate in screening or engage in early intervention services, and/or have difficulties accessing those services (Hackworth et al., 2018; Schoeman, Swanepoel, & van der Linde, 2017). While we know that parents are a rich source of information, the ways in which parents become aware of developmental concerns and their decision-making around seeking and accessing support is less well-researched. Factors influencing the decision to participate in early detection or intervention could include that not all parents have the same knowledge of developmental milestones, nor an environment in which they can compare their child's development to that of other children of the same age. Likewise, not all parents may have the same access to resources when they have developmental concerns about their child. To accurately identify children at risk and provide

intervention when concerns arise, it is important to understand not only the factors influencing the emergence of parental concerns, but also how these concerns relate to their decisions to seek out resources and/or additional help from health care professionals.

The aim of this study was to explore parents' perceptions of their child's development. Specifically, we were interested in understanding the factors influencing parents' perceptions of their child's development, and their decision-making regarding if and when to seek help from health care professionals.

2 METHODS

2.1 Design and methodology

For this qualitative study we chose to use a descriptive approach and semi-structured telephone interviews (Sandelowski, 2000) to better understand parents' perceptions regarding child development, and the factors influencing their decisions to seek additional help from health care professionals. In addition, parents were asked about their use of community services promoting development, and their recommendations to optimize those services. The study was approved by the ███████████████████████████████ Research Centre's ethic board. All participants provided their written consent.

2.2 Population and Recruitment

This study was the final phase of a three-phase research project describing the development of children aged 2 to 5 years in ███████ Canada. During Phase one, a convenience sample of families were recruited through social media and web advertisements, and in the local newspaper. Study information was also posted in daycares, public health programs, and private health care clinics, where community workers, educators, and public health workers assisted with recruitment. In Phase 1, 564 individuals completed an online survey which included the Ages & Stages Questionnaire – Third Edition (ASQ-3) (Squires & Bricker, 2009) . The ASQ-3 identifies

children at risk of developmental delay across gross motor, fine motor, social, communication, and problem-solving skills domains. As per the ASQ-3, a minimum number of questions needed to be completed for each domain for scores to be valid, and children considered to be at risk in at least one domain were identified and families invited to participate in Phase 2. Out of the 223 families who completed the ASQ-3, 100 children were identified as having a potential delay and 49 families consented to participate in Phase 2. This second phase consisted of a brief assessement conducted by a rehabilitation professional/student using the Developmental Indicators for the Assessment of Learning – Fourth Edition (DIAL-4) (Mardell & Goldenberg, 2011) and the Echelle de vocabulaire en images Peabody (EVIP) (Dunn & Theriault-Whalen, 1993). A subsample of families participating in Phase 2 were invited to participate in Phase 3 interviews. The reader is referred to Figure 1 for details of the recruitment process.

[Insert Figure 1 about here]

To participate in Phase 3, families had to have a child identified as being at risk of developmental delay based on the ASQ-3 (Phase 1). However, they could have either responded 'yes' or 'no' to at least one of the general ASQ-3 questions asking them if they had general concerns about their child's development (families were thus classified as reporting concerns or not). Likewise, families could have a child identified to be at risk or not at risk of developmental delay in Phase 2 (families were thus classified as having a child at risk or not at risk). We employed selective sampling (Crabtree & Miller, 1999) based on both sociodemographic characteristics and parental concern/Phase 2 child assessment results to ensure wide variation in our sample. From 18 invitations, 16 parents (13 mothers and 3 fathers) were recruited. Specifically, 14 (88%) families reported general concerns in Phase 1 and 11 (69%) were identified at risk in Phase 2. In addition, most parents already had consulted a health care professional other than their family physician (63%) and children were attending the publicly-funded daycare system (56%). Table 1 illustrates the sociodemographic characteristics of study participants.

[Insert Table 1 about here]

2.3 Data collection

Participating parents received a report (by email) of their child's Phase 1 and 2 results, and were asked to read the report prior to their interview. Interviews lasted approximatley 30 minutes (range 15 to 45 minutes). All interviews were conducted by a research assistant (█) with a background in physiotherapy and associated with the research team. A pilot interview training session with a patient partner was conducted under the supervision of the principal investigator who has extensive experience conducting qualitative research. The interviewer used open-ended questions with probing questions addressing: 1) p*arents' perceptions of their child's development* (reasons for presence/absence of concerns, what they did if they had concerns); 2) *parents' experiences with public, private, and community services promoting child development* (their knowledge, use and satisfaction with services); and 3) *parents' recommendations to optimize services promoting child development* (see Appendix 1).

2.4 Data analysis

Research data was analyzed using NVivo (version 12) software. Interviews were transcribed verbatim, translated to English for publication purposes, and analyzed using a thematic analysis (Braun & Clarke, 2006). The research team member who conducted the interviews (█) coded the transcripts. Subsequently, another team member (█) reviewed the codes, with coding disagreements discussed until a consensus was reached. Codes were reviewed by the principal investigator (█) and several meetings were held to regroup codes into themes. Relationships between themes were explored by looking at patterns across themes. Quotations freely translated from French were selected to illustrate the perceptions of parents regarding each theme.

3 RESULTS

Four themes were identified from the interviews: 1) Vision of child development influencing help-seeking behaviours: Natural or Supported?, 2) Internal and external sources contributing to

parents' level of developmental concern, 3) Using internal resources and struggling to access external resources, and 4) Satisfaction with services accessed and recommendations to access more support. Themes are described below, and Figure 2 illustrates how these 4 themes interacted together. Figure 2 also highlights how the vision of child development and sources of parental concerns influenced the level of concerns, helping us to understand how parents become concerned, as well as how parents' knowledge and their perceived access to resources influenced their decision whether or not to consult health care professionals.

[Insert Figure 2 about here]

3.1 Theme 1: Vision of child development influencing help-seeking behaviours: Natural or Supported?

Parents reported using their previous knowledge about normal development to make a judgement on whether or not they were concerned about their child. They described differing degrees of knowledge about normal development which was influenced by diverse factors such as educational, work, and life experiences. Two main, and opposing, visions about child development emerged: «Natural Development», where parents believed that each child develops at his/her own speed based on personality and preferences, and where developmental delays are caught up with time, and «Supported Development», where parents believed that child development needs to be stimulated, particularly when delays are observed. Parents ascribing to either vision of child development were equally likely to have developmental concerns about their child, but parents in the «Supported Development» group were more likely to believe their child would need help to overcome developmental challenges. As a consequence, they described being more likely to consult someone in their immediate environment (e.g. family member or educator) or someone they knew (e.g. family physicians), or to seek out and try strategies to foster their child's development. The perceived level of delay among parents also appeared to influence the level of concern, and the decision to seek help:

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My partner and I discussed it, but we weren't very concerned because we knew that when he entered kindergarten, he would probably catch up anyway.

(Participant #292, parental concerns, child not at risk of delay)

It's clear that if we don't help him, it is possible that there is a small delay that will accumulate until the beginning of school in a couple of years, it will continue, so that's why we want to push a little bit to help him.

(Participant # 123, parental concerns, child at risk of delay)

3.2 Theme 2: Internal and external sources contributing to parents' level of developmental concern

Parents spoke of internal sources including direct observation of their child, or comparison with other children as influencing their level of concern. Some parents described abnormal child behaviours, and often reported not having the specific knowledge about child development to interpret their observations, or to know what to do:

....when he is dancing, or turning in circles...he takes off the fluff from his socks and puts them in his nose, it is small weird things like that that makes us not understand why he does that. We try to find reasons, we don't know…I don't have the knowledge.

(Participant #123, parental concerns, child at risk of delay)

Others reported how a comparison with children of the same age helped to shape their perceptions of their child's development:

> *In fact, we noticed that there was a slight language delay. I noticed this because we have two other children, my oldest [children] are autistic and then when we knew they were autistic it started with a language delay...*

(Participant #527, parental concerns, child not at risk of delay)

External sources such as child care educators and physicians also appeared to influence parental concerns. Some parents described how feedback from educators served to validate or, in some cases, increase their level of concern. Parents reported relying on educators to inform them if development was delayed, only sharing their concerns with their family physician when they had sufficient concerns themselves. Parents described trusting the physician's medical expertise to then decide if they needed to consult another professional. In some cases, parents had no concerns, with concerns raised first raised by others:

> *In fact, the concerns for my child didn't come from me. It was all the parents around me and the youth workers at the nursery that were panicking. I was saying, he will talk when he is ready to talk.*

(Participant # 534, parental concerns, child at risk of delay)

3.3 Theme 3: Using internal resources and struggling to access external resources

Parents described using internal resources such as self-help strageies, searching online for activities, or consulting others in their environment including childcare educators and family members. Parents having a «Supported Development» vision were more likely to report trying self-help, home-based strategies before seeking external help. Some parents also reported using personal skills, like using organizational skills to establish a routine, or relying on their own experiences to try activities with their child:

> *I teach specialized education, so there are some tips that I've known for a while. I for sure shop around at the daycare and there are always little tips that come up and we use them and adapt.*

(Participant #169, parental concerns, child not at risk of delay)

External help was sought if initial strategies did not work, or when parents' concerns were greater than their perceived self-help skills. These included consulting health care professionals, requesting a referral to another health care professional, accessing community-based health care centres, or calling the provincial health-care information telephone service. Depending on their level of concern, their perceptions of their child's needs, and their personal resources, some parents indicated they would go to a hospital emergency department, a rehabilitation centre, or a private clinic. Whether the parents decided to use the public, private, or community-based programs depended on several factors: family income, perceived availability of support services (which was influenced by family income and sociodemographic factors), the type of help that they were seeking, and the recommendations of individuals in their environment:

> *It was my yoga teacher that found my child stiff. We couldn't fold his legs like other babies. That's when she came to see me to say, "I think you should go visit an osteo."*
> (Participant #169, parental concerns, child not at risk of delay)

Accessibility to external resources, mostly publicly-funded services, was however perceived to be quite limited by parents because of wait time, other requirements such as the need for a referral, and general eligibility criteria, as well as the lack of child development services. This greatly influenced the decisions parents made to seek help, and their ability to receive the desired services, and led to the use of community-based or even private programs. Many participants reported difficulties getting appropriate referrals from their physicians to consult a professional:

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> *[My doctor is] not very accessible and because he's been a doctor for a really long time and it seems like he's not into it anymore….I have trouble communicating with him and making him understand my expectations. It also seems like he doesn't really know the resources anymore.*

(Participant # 544, parental concerns, child at risk of delay)

Communication challenges with doctors were often reported, as parents perceived their concerns were often disregarded. When referrals were made, these sometimes got lost within the health care system due to poor communication between clinics as well as complicated administrative procedures. Other factors influencing parents' help-seeking included short appointments and physicians not having concerns about the child. Parents felt that they know their child best and wanted physicians to have more confidence in their judgement and to take them more seriously:

> *Exactly [I would like doctors to do something to help], they could consider parents' concerns seriously. Sometimes, the way they talk, it's like they take you for an idiot. They act with condescendence and that annoys me!*

(Participant #335, parental concerns, child at risk of delay)

The lack of accessibility and long waiting time increased parents' level of concern in some cases, could become a family stressor, and led many parents to use the private health sector as a method of choice, for those who could afford to do so:

> *In the public sector, from what I understand, it's always long. It's a big machine. They can't just tell you, "ok, all good, you have a problem and I'll take care of it." It's as if they must fill out never-ending reports and validate the problem with 60 people first. I didn't need that; I had an immediate need. So, when it's urgent, I don't think the public sector is responsive enough, not at all. That's why I go to the private sector.*

(Participant 534, parental concerns, child not at risk of delay)

I don't know if they are lacking resources or they are hard-pressed. The waiting time really needs to be diminished. In some cases, even urgent ones, they still have long waiting lists. I would say that in this moment, what stresses me, is that my son is 3 and a half years old. There's one year and a half of waiting time for the autism diagnosis and right now, there's no evolution but it's a crucial developmental period for him.

(Participant #23, parental concerns, child not at risk of delay)

Despite system navigation challenges, some parents did appear to know where to go when they needed support. However, most parents said they would try at-home strategies first, and would struggle to know where to go in the public, private, or community-based sectors. Most said they tended to wait to seek help and only did so once their level of concern exceeded their own acceptable threshold. They also indicated they would have liked to have received information about all of the resources and programs available to guide them during their child's early years prior to school entry.

3.4. Theme 4: Satisfaction with services accessed and recommendations to access more support

Many participants reported using community-based programs, and that these were perceived to be more accessible than public services. These programs were sometimes enough to respond to their needs. For parents who received services from the public and/or private systems, most described positive experiences and were satisfied with the quality of the services and competency of the professionals they encountered. When a diagnosis was given, many more resource options were offered to the parents with follow-up and/or referrals made for other services:

> *She was proactive, she was always looking at my child's development. She saw him for a year and a half or two years. She was always looking at how he was developing, his new developments since the consultation, etc.*
>
> (Participant #476, no parental concerns, child at risk of delay)

Many parents provided suggestions to improve both public services and community-based programs, to enhance parents' knowledge of the available resources and accessibility of support services, and to decrease wait times. Such suggestions included more information during prenatal classes or in booklets given following pregnancy, or regrouping programs and service information to enhance parents' ability to navigate through the system as a whole. Many parents indicated they currently didn't know about most of the existing support services:

> *We heard about [one specific program] during prenatal courses I think, but it was the only one we knew about. Actually, I was shocked when I answered the surveys and found out about the million services that I didn't know about.*
>
> (Participant #476, parental concerns, child not at risk of delay)

Most parents recommended changes to increase the accessibility of public services, including adding front-line professionals:

> *[having specialists outside of hospitals], I think would make a difference and if we could schedule an appointment when we need to see a family doctor, you know, when you don't have a referral?, you can't consult a pediatrician at the hospital. For someone who doesn't have a family doctor or who doesn't go through the emergency room first, it's difficult to see a pediatrician or a specialist.*
>
> (Participant #123, no parental concerns, child at risk of delay)

They also requested more support throughout their child's development, particularly between 2 and 5 years when they felt services were less available. They mentioned their need to be reassured and to have others validate their perceptions of whether or not their child's development was typical:

> *You know when you have a nurse come over to your house when you have a baby? It would be fun to continue that, have the nurse come into your environment, look at different things with you, the toys you have, how you're arranged, give little tips based on your child. That could be interesting.*

(Participant #381, parental concerns, child at risk of delay)

4 DISCUSSION

This study explored parents' perceptions of their child's development in an effort to understand the factors influencing those perceptions, as well as their decision-making regarding if and when to seek help from health care professionals. We found that parents had differing visions of their child's development, with some believing it unfolds more naturally and others believing development needs to be supported. Thus far, the literature had focused mostly on the impact of families' socioeconomic background on their perception of children's needs (Porterfield & McBride, 2007) and on their engagement in childhood support services (Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Phoenix & Rosenbaum, 2015). Our findings highlight that beyond socioeconomic status, it is crucial to understand parents' vision of development in order to engage meanginfully with them to support them and their child. These results suggests the need for those who support parents to recognize parents' unique vision of development and then to tailor their interactions with parents, either by helping them to recognize the importance of early intervention or by acknowledging their concerns.

Parents who participated in this study reported relying heavily on health care professionals', educators' and others' observations to confirm/validate or help them to adjust their perceptions of their child's development. This is consistent with the literature highlighting mismatch between parents' perceptions and health care professionals assessment, and stressing the importance of engaging front-line professionals in early detection (Canadian Task Force on Preventive Health, 2016; Steenis, Verhoeven, Hessen, & van Baar, 2015). Health Care Professionals should not be involved only in assessing children directly, but rather also collaborate with educators to identify children at risk of delays (Hillier, Civetta, & Pridham, 2010). Our findings also imply that broader awareness of children's development might be required among all those involved in early identificatoin, with community members in particular becoming more aware of what constitutes typical child development to identify and share concerns about children who might be struggling with their peers.

This study is one of the first to identify that beyond the level of concerns about their child's development, parents reported taking into account their perceived access to resources in their decisions whether or not to seek professional help. Difficulties accessing rehabilitation services was a factor already well documented in the literature (Bailey et al., 2004; Feldman, Champagne, Korner-Bitensky, & Meshefedjian, 2002; Foley & Camden, 2015; Phoenix & Rosenbaum, 2015), but this study adds to this research by highlighting the importance of first and foremost hearing and listening to parents' concerns about their child's development, building on their existing internal resources, and helping them navigate the system to find external resources when the support required exceeds their perceived knowledge and abilities. Parents often report difficulties navigating the system and not being heard with regards to their concerns for their child(King, Cathers, King, & Rosenbaum, 2001). Our study echoes others' recommendations to address parental concerns as a strategy both to support children's development, but also to improve families' wellbeing (Majnemer et al., 2019).

It is important to note that many individual factors likely influence parents' levels of concern, and their decisions whether or not to consult others for help. In this study, there were a group of parents who reported no developmental concerns despite the presence of potential developmental delays, but the reasons for this are not entirely clear from our findings. One

possibility is that this particular group of parents may not have had many opportunities for developmental comparisons in their environments, and so were less likely to have concerns. Another possibility is that individuals in their environments had concerns and may have even expressed those concerns, but that the concerns did not rise to the threshold level for that parent to be worried or to seek services or resources. Alternatively, parents may have been experiencing some denial about their child's development, or felt overburdened with other priorities to seek help. All of these factors warrant further study.

Recommendations voiced by parents to improve services to support children's development are aligned well with much of what is known in the literature, but provide additional practical applications. Parents indicated they wanted more information both about child development and available programs to support them. This is consistent with the literature indicating that miscommunication between health care professionals and families might be a major area of dissatisfaction for families (Bailey et al., 2004; King et al., 2001). It also suggests that beyond interpersonal communication, information should be disseminated more broadly into the community. Health promotion activities could be an interesting avenue to increase parents' sense of competence and provide parents with information about the diverse options of services available to support them and foster their child's development. Other recommendations voiced by families included the need to have more front line service providers dedicated to children's development. Research confirms these well-known issues in many health care systems, where rehabilitation services might be available for children with formal disabilities but where early intervention support services might not be available, particularly when no diagnosis has yet been given (Foley & Camden, 2015). There are and several interesting models worldwide where families can walk-in and access services that may point the way forward (Bailey et al., 2004). Also, having health care teams with rehabilitation professionals embedded into communities, with the dedicated mandate to hear parents' concerns, respond to their questions, support them, and offer services or connect them with the required services would greatly help families. Such community teams may be a means to address the difficulty of access to available services and lack of information regarding services that parents reported in this study.

5 LIMITATIONS

The transferrability of this study is limited by the small number of participants, from a very specific health care system. It is also important to note that most parents in our study reported developmental concerns for their child, which limits our ability to understand the views of parents who report no concerns. Likewise, as we did not have access to full developmental assessments for the children involved, we could not confirm the level of parental concern with objective developmental delay. However, we explored perceptions from different groups of parents (i.e. those reporting concerns or no concerns, whose child were and were not identified at risk of delay in Phase 2) and did not find substantial differences in the ways they spoke about the themes that emerged. In addition, the parents who took part in this study were a fairly heterogeneous group, with the majority of parents highly educated, and from a similar socioeconomic background. Despite this, the fact that parents in this study struggled to decide when to seek help, and where to go for that help, suggest that many parents might face similar challenges, enhancing the study's overall external validity. These findings underscore the need to provide all parents with resources about development, independent of their education and/or socioeconomic background, because even when parents are highly educated, they may not necessarily have the knowledge that is required to help them make judgements about their child's development, and on how to seek readily available resources.

6 CONCLUSIONS

The early identification of children who are at risk of developmental delay is crucial to support families in promoting healthy child development and to prevent the onset of secondary challenges. Families use a variety of strategies to access resources and services for their children when they have developmental concerns. It is important for educators and health care professionals to help parents recognize when difficulties exist and to help them access and navigate the resources available. Additionally, tailoring interactions to parents' understanding and beliefs about child development will help them to be heard and to seek professional help when appropriate and necessary.
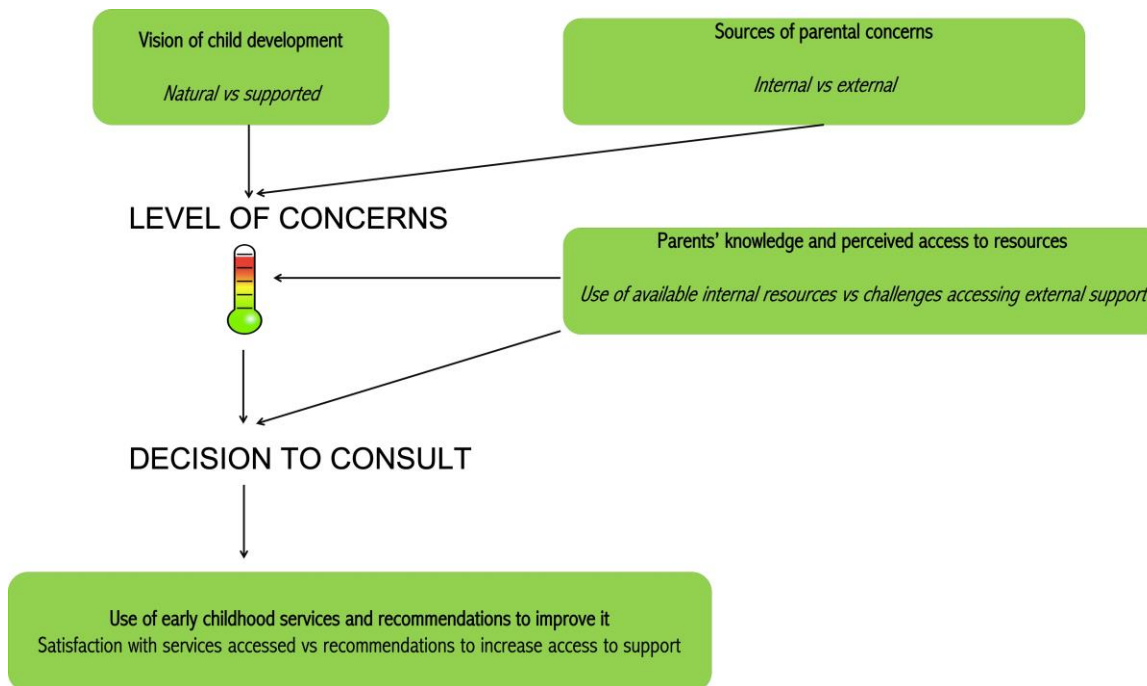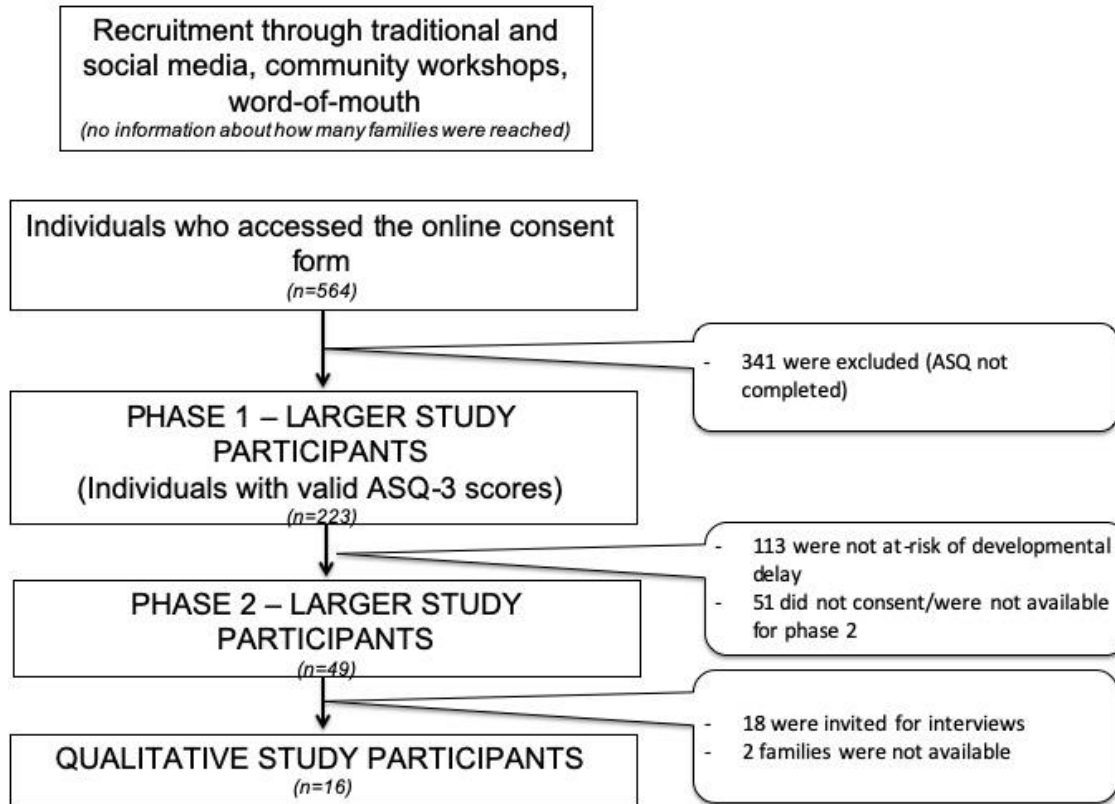
Key Messages

- Parents differ as to whether they believe child development unfolds naturally or whether development must be supported, suggesting a need to tailor our interactions based on parent's beliefs or vision about development

- It is important to support parents ascribing to a 'Natural Development' vision through increased awareness of developmental services and resources when they note concerns for their child; for parents who ascribe to a 'Supported Development' vision and note developmental concerns, validation of their concerns and assistance in implementing strategies and/or navigating the system will be crucial

- Parents rely on their own observations of their child and through comparisons with other children to make judgements about potential developmental delays. They also highly trust health professionals, educators and others in their environment, highlighting the need for professionals to make available and accessible child development resources and support services

- Health care professionals including rehabilitation specialists should be part of community-based front line specialists available and accessible to support children and their families when they express developmental concerns or developmental concerns are observed

Recruitment through traditional and social media, community workshops, word-of-mouth
(no information about how many families were reached)

Individuals who accessed the online consent form
(n=564)

- 341 were excluded (ASQ not completed)

PHASE 1 – LARGER STUDY PARTICIPANTS
(Individuals with valid ASQ-3 scores)
(n=223)

- 113 were not at-risk of developmental delay
- 51 did not consent/were not available for phase 2

PHASE 2 – LARGER STUDY PARTICIPANTS
(n=49)

- 18 were invited for interviews
- 2 families were not available

QUALITATIVE STUDY PARTICIPANTS
(n=16)

Vision of child development

Natural vs supported

Sources of parental concerns

Internal vs external

LEVEL OF CONCERNS

Parents' knowledge and perceived access to resources

Use of available internal resources vs challenges accessing external support

DECISION TO CONSULT

Use of early childhood services and recommendations to improve it
Satisfaction with services accessed vs recommendations to increase access to support

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References

Bailey, D. B., Jr., Hebbeler, K., Scarborough, A., Spiker, D., & Mallik, S. (2004). First experiences with early intervention: a national perspective. *Pediatrics, 113*(4), 887-896. doi:10.1542/peds.113.4.887

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101. doi:Doi: 10.1191/1478088706qp063oa

Canadian Task Force on Preventive Health, C. (2016). Recommendations on screening for developmental delay. *CMAJ, 188*(8), 579-587. doi:10.1503/cmaj.151437

Crabtree, B. F., & Miller, W. L. (1999). *Doing Qualitative Research*: Sage Publications Inc.

Desrosiers, H., & Tétrault, K. (2012). *Les facteurs liés à la réussite aux épreuves obligatoires de français en sixième année du primaire: un tour d'horizon », étude longitudinale du développement des enfants du québec (éldeq 1998-2010) – de la naissance à 12 ans*. Institut de la statistique du québec.

Dunn, L. M., & Theriault-Whalen, C. (1993). *Échelle de vocabulaire en images Peabody: EVIP*. Toronto: PSYCAN.

Ertem, I. O., & WHO, X. (2012). *Developmental difficulties in early childhood: prevention, early identification, assessment and intervention in low- and middle-income countries: A review*. Geneva: Switzerland: World Health Organization.

Feldman, D. E., Champagne, F., Korner-Bitensky, N., & Meshefedjian, G. (2002). Waiting time for rehabilitation services for children with physical disabilities. *Child Care Health Dev, 28*(5), 351-358.

Foley, V., & Camden, C. (2015). Contribution de la santé publique aux services de réadaptation pédiatriques en déficience physique. [Contribution of Public Health to Paediatric Physical Disability Rehabilitation Units]. *Santé Publique, S1*(HS), 95-103. doi:10.3917/spub.150.0095

Glascoe, F. P. (1997). Parents' concerns about children's development: prescreening technique or screening test? *Pediatrics, 99*(4), 522-528. doi:10.1542/peds.99.4.522

Glascoe, F. P. (2003). Parents' evaluation of developmental status: how well do parents' concerns identify children with behavioral and emotional problems? *Clin Pediatr (Phila), 42*(2), 133-138. doi:10.1177/000992280304200206

Hackworth, N. J., Matthews, J., Westrupp, E. M., Nguyen, C., Phan, T., Scicluna, A., . . . Nicholson, J. M. (2018). What Influences Parental Engagement in Early Intervention? Parent, Program and Community Predictors of Enrolment, Retention and Involvement. *Prev Sci, 19*(7), 880-893. doi:10.1007/s11121-018-0897-2

Hillier, S. L., Civetta, L., & Pridham, L. (2010). A systematic review of collaborative models for health and education professionals working in school settings and implications for training. *Educ Health (Abingdon), 23*(3), 393.

Irwin, G. L., Siddiqui, A., & Hertzman, C. (2007). *Early Child Development: A Powerful Equalizer*. Vancouver, BC: Human Early Learning Partnership (HELP).

King, G., Cathers, T., King, S., & Rosenbaum, P. (2001). Major elements of parents' satisfaction and dissatisfaction with pediatric rehabilitation services. *Children's Health Care, 30*(2), 111-134.

Majnemer, A., O'Donnell, M., Ogourtsova, T., Kasaai, B., Ballantyne, M., Cohen, E., . . . Parent, P. (2019). BRIGHT Coaching: A Randomized Controlled Trial on the Effectiveness of a

Developmental Coach System to Empower Families of Children With Emerging Developmental Delay. *Front Pediatr, 7*, 332. doi:10.3389/fped.2019.00332

Mardell, C., & Goldenberg, D. S. (2011). *Developmental Indicators for the Assessment of Learning – 4th Edition manual*. Bloomington, MN: Pearson.

Paquette, K., Japel, C., Paradis, H. . (2016). L'association entre l'état de vulnérabilité psychosociale pendant l'enfance et le rendement scolaire au primaire. *Canadian Journal of Education/Revue canadienne de l'éducation, 39*(2), 1-25.

Phoenix, M., & Rosenbaum, P. (2015). Development and implementation of a paediatric rehabilitation care path for hard-to-reach families: a case report. *Child Care Health Dev, 41*(3), 494-499. doi:10.1111/cch.12194

Porterfield, S. L., & McBride, T. D. (2007). The effect of poverty and caregiver education on perceived need and access to health services among children with special health care needs. *Am J Public Health, 97*(2), 323-329. doi:10.2105/AJPH.2004.055921

Reijneveld, S. A., de Meer, G., Wiefferink, C. H., & Crone, M. R. (2008). Parents' concerns about children are highly prevalent but often not confirmed by child doctors and nurses. *BMC Public Health, 8*, 124. doi:10.1186/1471-2458-8-124

Sandelowski, M. (2000). Whatever happened to qualitative description? *Res Nurs Health, 23*(4), 334-340.

Schoeman, J. C., Swanepoel, W., & van der Linde, J. (2017). Developmental screening: predictors of follow-up adherence in primary health care. *Afr Health Sci, 17*(1), 52-61. doi:10.4314/ahs.v17i1.8

Squires, J., & Bricker, D. (2009). Ages & Stages Questionnaires Third Edition (ASQ-3). Retrieved from https://agesandstages.com/

Steenis, L. J., Verhoeven, M., Hessen, D. J., & van Baar, A. L. (2015). Parental and professional assessment of early child development: the ASQ-3 and the Bayley-III-NL. *Early Hum Dev, 91*(3), 217-225. doi:10.1016/j.earlhumdev.2015.01.008

Tang, M. H., Lin, C. K., Lin, W. H., Chen, C. H., Tsai, S. W., & Chang, Y. Y. (2011). The effect of adding a home program to weekly institutional-based therapy for children with undefined developmental delay: a pilot randomized clinical trial. *J Chin Med Assoc, 74*(6), 259-266. doi:10.1016/j.jcma.2011.04.005

WHO, X. (2018). *Nurturing Care for early childhood development*. Geneva, Switzerland: World Health Organization (WHO).