Dr. David Joyce

FAMILY PHYSICIAN, CLINICIAN SCHOLAR, AND RESEARCHER

Dr. David Joyce is a family physician at the Pender Community Health Centre in Vancouver and a Clinical Assistant Professor with the UBC Department of Family Practice. He recently completed the R3 Clinical Scholar Program and has an active research program on developmental screening in primary care settings.

Dr. Marjolaine Limbos

PSYCHOLOGIST, CLINICAL INSTRUCTOR AND RESEARCHER

Dr. Marjolaine Limbos is a registered psychologist, specializing in child clinical psychology. She is a staff psychologist with the Renal and Multi-Organ Transplant teams at BC Children's Hospital, and works in private practice in Vancouver. Her research interests relate to screening for autism, developmental and learning problems in children, particularly those with complex genetic and medical conditions.

The Bear Bones: How prevalent is developmental delay in children?

David Joyce: Developmental delay affects anywhere between 10 and 15 per cent of children. In the last census, Statistics Canada showed that it is the most disabling condition in children under the age of six. In our study, we randomly examined 334 children and found that 10 per cent had some form of developmental delay. As a family doctor, I cannot say that I see one in ten children with developmental delay, but that is the fact…

TBB: How do you define the term developmental delay?

Marjolaine Limbos: Developmental delay is a broad term that includes developmental disabilities as well as delays in other areas of development such as motor, cognitive, or receptive and expressive language. Only a subset of the group with developmental delay will have cognitive or intellectual disabilities, so there is a distinction to be made there. In our study, we looked at children who were scoring below the 10th percentile on either their cognitive or developmental measures as well as children who had receptive or expressive language or motor delays. There are different ways to describe delays in cognitive development. One is to say that a child is falling behind their peer group – maybe they're scoring in the low-average to below-average range or below the 25th percentile. In our study, we looked at children below the 10th percentile because we found that that it was too liberal to look below 25th percentile.

TBB: What age do you start testing for developmental delay?

DJ: There is such variability in the age that children meet 'normal' developmental milestones. Our study of two developmental screening tools – the Ages and Stages Questionnaire (ASQ) and the Parents' Evaluation of Developmental Status (PEDS) – found that the tests were very useful. Unaided, family physicians and pediatricians struggle to identify children with developmental delay. These screening tools have a set of questions for any given age-range. Screening for developmental delay can begin in infancy, but we studied it in preschool children aged one to five.

TBB: Can you describe the different types of screening tools?

DJ: Most Canadian family physicians use a truncated screening tool which is included in the Rourke Baby Record. The Rourke is a child monitoring tool that includes a

GPs may be the only professionals that have access to the pre-school child and the ability to make further referrals if there are concerns [about developmental delay].

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number of manoeuvres. For example, it indicates that I should measure and weigh the child, give the child DPTP vaccine, remind the parents to switch to a different car seat, and also ask a few questions about development. This tool, however, has not been validated for developmental screening, so doctors might be falsely assured that they are doing an adequate developmental check.

The ASQ and the PEDS are quite different. Both are brief and parent-administered. Doctors are busy, so having a tool that is parent-administered and then checked by the doctor can save a lot of time. As such, both tests are ideally suited for a primary care setting. The PEDS uses 10 open-ended questions asking parents about their concerns. One question is, "Do you have any concerns about your child's ability to communicate?" The response options would be "yes, no, or a little." The test leaves a space where parents can write comments if they have a concern. It is a simple test that takes five minutes to complete and could be handed to someone in a waiting room. It doesn't take too much planning or involvement of the child.

The ASQ has more psychometric questions, takes 15 minutes to complete, and is divided by age-group. Each age-group section has about 30 items. The parent is asked if their child is able to perform a specific task such as "does your child throw a ball in a forward motion?" (at 18 months) or "is your child able to help get himself or herself dressed?" (at two and a half years of age). It asks parents to do the test and if they don't know the respsonse, it asks them to try the task with their child. There is a specific test in each of the domains – speech, expressive speech, motor, receptive, cognitive, and adaptive functioning. The ASQ is similar to a test that a psychologist would perform, but much simpler and very brief.

TBB: Who sets the guidelines for testing on developmental delay?

DJ: The American Academy of Pediatrics, whose committee on developmental delay suggests screening at 9, 18, and 30 months, provides the best guidelines. In Canada, we focus more on the 18-month well-baby visit because there is a lot you can look for at that age. These guidelines are not as formal but have been set by the Ontario College of Family Physicians. It's also a practical time to screen because the vaccine schedule changes after 18 months – there are no more vaccinations until the child begins school. We're proposing that family

physicians administer the screening tools because GPs may be the only professionals that have access to the pre-school child and they have the ability to make further referrals if there are concerns.

TBB: Who scores the test?

DJ: Both tests have manuals that describe scoring, but it is very simple. Usually it is an administrative person who scores the test in the family doctor's office. The health professional reviews it, makes a clinical judgment, and if needed, makes a referral.

TBB: What made you decide to research this topic?

DJ: This study came out of Marjolaine's PhD in psychology which looked at learning disabilities and how teachers could help with early identification. We did a preliminary survey in Ontario and out of 150 family physicians, no one used the ASQ and PEDS, a handful used the Nippissing District Developmental Screen (NDDS), and even the Rourke Baby Record wasn't performed by everyone. As a family doctor, I didn't do much in the way of screening for developmental delay in the past. I'd read about the tests and knew they were being discussed in the literature, but in practice I just wasn't seeing them used.

ML: In psychology, there is this idea that we don't have tests available to identify problems with children early on. Or often people say, "They're young and they'll grow out of it" or "let it be and see what happens." Some children do grow out of their difficulties, but some do not and the earlier the intervention is put into place the better the outcome is for the child. In some children, we can see the problems right away and want to intervene before there are long-term effects and problems start to be compounded by social and emotional issues and peer relations.

TBB: How did you recruit participants for your study?

DJ: We started our study in Ontario and recruited children who were presenting to their family physician for any reason, not necessarily developmental delay. Eighty primary care providers allowed us to recruit from their offices and 20 became involved in the larger study. Parents self-referred from posters and we had a summer research student recruiting from waiting rooms, so it was a convenience rather than random sample.

TBB: Can you describe how the tests for developmental delay were conducted?

DJ: We had parents self-administer the ASQ, PEDS, NDDS, Rourke Baby Record and the Modified Checklist for Autism (MCHAT); at the same time, Marjolaine did a battery of psychological testing on the children in a separate room. The parents completed a demographic survey to inform us about their child's developmental history, signs of developmental delay, and medical problems. We also asked about the parents' family history, drug use, smoking, socio-economic status, and ethnic background. In addition, we had permission to review the medical charts at their doctor's office. At the end of the study, we had the results of the screening tests, the results of the gold standard to compare against, and demographic information about the children. We chose to compare the ASQ and the PEDS first because they seem to be a hot topic in the medical literature at this time.

TBB: What is the gold standard and why is it significant?

ML: The gold standard is an actual assessment by a psychologist, administration of well-established and standardized psychological measures, and giving an adaptive behavior interview. All three pieces are used to identify kids at risk. No one in previous studies had integrated an adequate gold standard as a comparison in their methodology, so we included it to improve on what had been done in the past.

TBB: What were your preliminary findings?

DJ: The ASQ has some advantage over the PEDS. We found that the ASQ has a sensitivity of 82 per cent and specificity of 78 per cent. Ratings above 70 per cent are considered acceptable and above 80 per cent is ideal. For the PEDS, we saw that sensitivity was still adequate at 74 per cent, but its specificity was only 64 per cent. If you have a low specificity it means that you will be telling a lot of kids there is a problem when there isn't one. You don't want the specificity to fall too low.

Even if we looked at the children who met stringent criteria for developmental disability, we saw that the ASQ stayed in the 75 to 80 per cent range for sensitivity and specificity across the age groups and across definitions. The PEDS always seemed to fall a little short in either the sensitivity or the specificity.

TBB: What impact does this study have on the current research?

DJ: There have been other studies comparing the ASQ and the PEDS, but they have never been administered together in a single study. Our study addresses this issue and also specifically addresses the group under the 10th percentile for developmental delay. If we only took the most disabled children it is different than looking at delayed children, which is also different than evaluating 25 per cent of all children.

In many of the other studies, researchers used a single developmental category or only administered the gold standard to those who scored positive on the screening test, which means that they know nothing about the false negative rates. Sensitivity and specificity are calculated based on formulas using true positive, false negative, true negative rates, and false positive rates, so when you only apply the gold standard to the positive screens you don't know if children who test negative were truly negative. Assuming that all negatives were true negatives really throws off your calculation of sensitivity.

ML: Some past studies of these screening tools indicated that they seemed to be failing, but if you haven't tested the

children correctly then you can't really say that for sure. It is important to correctly classify children as delayed or not using an adequate gold standard.

DJ: It's interesting to note that family doctors were getting the message from the Canadian Task Force on Preventive Health care that there is sufficient evidence to exclude developmental screening form periodic health exams. This recommendation was given as a result of a single study done in Canada where children were screened and then followed up. The problem was that the study used the Denver Developmental Screening Test, which has very low sensitivity and specificity. That study also didn't offer much in the way of intervention for those identified with problems, so it is no wonder that the study showed no benefit of screening.

TBB: Do you think screening tools should be implemented in a primary care setting?

DJ: Absolutely. As a family doctor, there are so many things to keep your eye on, so it's nice to have a tool that simplifies the process. You still have to apply your clinical judgment, but it is useful to have a validated screening test that lays out the levels of development at any given age. It has the potential to make a difference. We know that 10 per cent of children have a developmental delay – that's quite a large number. We also know that about 30 per cent of children who have problems aren't identified until they get to school, so children are seeing their doctor through this pre-school period and not being identified.

TBB: How do you start to implement it into family practice?

DJ: It takes a concerted effort to add one more new test to a doctor's repertoire. In Ontario, there is a big push to use the Rourke and NDDS at the 18 month well-baby visit. There is an educational campaign taking place to promote their use. The government of Ontario bought the rights to the NDDS, so it is free for Ontario physicians to download and

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doctors can also bill the health plan for the screening. This may overcome many of the barriers to using screening tools. No similar program exists in BC that I am aware of.

TBB: Why do you think they chose the NDDS over some of the other available tools?

DJ: Family physicians in Canada don't seem to be aware of the ASQ and the PEDS. A group of experts in Ontario developed the NDDS – psychologists, pediatricians, family physicians, and leaders in the field of developmental delay. The NDDS is also brief, parent-administered and easy to interpret, but lacks validation. So I'm not sure why the NDDS was chosen over other well validated tests. We studied the NDDS in our cohort and we're going to roll-out that data soon.

TBB: What would you say that is the most important thing you've learned from the research project or the process?

DJ: Parents were happy to participate and would spend three hours with our team. Parents want to know about their child's development and get help if they are having problems. I learned that it is the process of doing this screening with the families that is helpful. Dialoguing with parents gives them information that they can take home and helps them cope.

Even if the tests are used as a stepping stone to offer parents some advice, to support the family, or to follow-up, it can help all children develop better, delayed or not.

ML: There were a couple of severely challenged kids who were detected from our screening process who hadn't been identified before, so that demonstrated that this process can be useful.

TBB: Is there one message that you want to get out to family physicians?

DJ: Doctors need to see the benefits of testing for developmental delay and keep an open mind. They should know that there are easy ways to screen children. They should also be confident that when we identify children early on, there is effective treatment that will benefit the children now, and more importantly, down the line.

the BEAR BONES