BRITISH COLUMBIA DISABILITY COLLECTIVE

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Analysis identifies serious shortcomings in province's proposed tools for determining which children with disabilities qualify for support.

Vancouver, BC– In late 2021, BC's Ministry of Children and Family Development (MCFD) announced sweeping changes to how it will provide funding and services to children and youth with disabilities. Since that time, parents, advocates, and service providers have raised questions and concerns about various elements of the proposed new system. This includes the needs-assessment tools the new system will rely on to decide which children with disabilities should receive support. Caregivers are expected to fill these in online.

In a recent letter to MCFD, a collective of organizations who work with and support families of children with disabilities noted that **more consultation is needed to ensure that over reliance on these assessment tools will not cause harm or exclude children and families** from the supports and services they need. An analysis of previous research by Dr. Pat Mirenda, Professor Emerita (University of British Columbia), raises questions about the proposed tools that point to exactly what families and advocates fear.

To date, MCFD has not provided details of how it intends to use these pediatric evaluation tools, known as PEDI-CAT and Vineland 3. The only jurisdiction where this combination has been used internationally is Australia, where a study revealed that the PEDI-CAT tool **disqualified 25% of children** whose parents were concerned and whose pediatricians referred them for assessment. The Vineland-3 tool disqualified 4% of children.

About Us: The British Columbia Disability Collective is a group of BC-based organizations, as well as clinicians, researchers, and businesses with hundreds of years of combined experience supporting tens of thousands of children and youth with disabilities and complex needs. We are jointly writing this letter to express our concerns with the Ministry of Children and Family Development's (MCFD) sudden decision to transform the existing support network for children and youth with disabilities to a system of generalist hubs while simultaneously eliminating individualized funding.

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EXECUTIVE SUMMARY

Assessment for Eligibility and Service Support Needs: Overview and Questions

The Ministry of Children and Family Development (MCFD) has selected two assessment tools that caregivers will complete online to determine whether their child will be eligible for "disability services" at the "Family Connection Hubs" MCFD is planning to create throughout BC.

Both the PEDI-CAT and the Vineland-3 tools are meant to assess a person's abilities in areas such as daily living, communication and social skills. Both tools are widely used with children and youth with a variety of physical and/or behavioral conditions and yield scores that compare a person with a disability to same-age peers without a disability.

Scores obtained via parent report are known to be less reliable than those obtained via a structured interview by a skilled clinician, as they require that the caregiver fully understands the questions and how the rating scale works. In addition, neither tool is available in the minority languages that are most common in BC (e.g., Mandarin, Cantonese, Punjabi, Tagalog).

MCFD has not provided any details of how it intends to use the PEDI-CAT and Vineland-3 scores. The only jurisdiction where this has been used internationally is Australia where they have set cut-off scores on both of these measures to establish service eligibility and support needs for children and youth with disabilities.

- A rare study of this issue done in Australia (Milne et al., 2019) revealed that PEDI-CAT cut-off scores disqualified 25% of children whose parents were concerned and whose pediatricians referred them for assessment. The Vineland-3 disqualified 4% of children.
- In addition, the Vineland-3 identified significantly more children as needing higher levels of support in multiple areas, compared to the PEDI-CAT.
- In practical terms, use of similar cut-off scores by MCFD could disadvantage children with, for example, fetal alcohol spectrum disorder (FASD), dyslexia/learning disability, and ADHD. In addition, children affected by cerebral palsy, Down syndrome, and other neurodevelopmental conditions, as well as those whose autistic symptoms are less evident, could be denied service.

- Many questions about the intended use of these tools remain:
  - What cut-off score(s) will be used to determine eligibility for service?
  - What cut-off score(s) will be used to determine levels of service support?
  - How will service supports be allocated between different clinical specialities?
  - Will cut-off scores be set by MCFD or will Hubs be allowed to set their own?
  - Research studies of both measures have shown that the scores obtained for some young children and for individuals with more significant functional needs may result in an over-estimation of their ability and an under-estimation of their support needs. How will this issue be addressed?
  - How will the assessment for eligibility and service needs be completed by caregivers whose primary language is not available in translated versions of the two measures, or by caregivers with limited reading and/or writing skills?
  - How often will eligibility and service support needs be re-assessed?
  - If a child improves, will supports be terminated and if so, when and how?

ASSESSMENT FOR ELIGIBILITY AND SERVICE SUPPORT NEEDS: DETAILED REVIEW

The Ministry of Children and Family Development [MCFD] has selected two assessment tools -- the Pediatric Evaluation of Disability Inventory -Computer Adaptive (PEDI-CAT) and the Vineland Adaptive Behaviour Scales-3rd edition (Vineland-3) -- that caregivers will complete online to determine whether their child will be eligible for "disability services" at the "Family Connection Hubs" MCFD is planning to create throughout BC. This brief provides information about these two measures and questions related to their use.

What is the PEDI-CAT?

The PEDI-CAT is a computerized adaptive caregiver assessment that measures Daily Activities (e.g., dressing, feeding), Mobility (e.g., walking, getting in and out of a car), Social/Cognitive skills (e.g., asking for help when needed, number recognition), and Responsibility (i.e., the extent to which the caregiver or the child takes responsibility for managing complex, multi-step life tasks). It is designed for use with children and youth from birth to 20 years of age with a variety of physical and/or behavioral conditions. It is available in English, US Spanish, Brazilian Portuguese, Danish, Dutch, French Canadian, German, Italian, Norwegian, and Swedish. It takes between 12-20 minutes to complete, depending on the child's age and ability. It is intended to be used for (a) identification of functional delay, (b) examination of improvement for an individual after intervention, and (c) evaluation and monitoring of group progress in program evaluation and research.

For the three domains of Daily Activities, Mobility, and Social/Cognitive, a caregiver rates a person's ability to perform each behaviour/skill on a 4-point scale, with responses ranging from 'Unable' to 'Easy.' The Responsibility domain has its own 5-point scale with responses ranging from 'Adult/caregiver has full responsibility; the child does not take any responsibility' to 'Child takes full responsibility without any direction, supervision or guidance from an adult/caregiver.' Both normative scores (i.e., scores that compare a child to same-aged peers without a disability) and scaled scores (i.e., scores that do not compare a child to same-aged typical peers and can be used to monitor a child's change over time for intervention planning) are generated by the PEDI-CAT program.

What is the Vineland-3?

The Vineland-3 measures skills in three primary domains: Communication (e.g., following instructions, naming objects), Daily Living Skills (e.g., dressing, feeding), and Socialization (e.g., has friends, talks with others about shared interests). There are also optional domains that measure Motor skills (e.g., walking, throwing a ball) and Maladaptive Behaviour (e.g., depression, aggression, tantrums). It is designed for use with individuals from birth to 90 years of age with a variety of physical and/or behavioral conditions and is available in English and US Spanish only. A caregiver can complete it online or via paper and pencil; it can also be completed as a interview by a trained clinician (requiring 30-40 minutes). It is intended to be used for (a) diagnosis, (b) qualification for special programs, (c) progress reporting, (d) program and treatment planning, and (e) research.

Scoring is based on the three primary domains only (i.e., excluding Motor Skills and Maladaptive Behaviour). The caregiver rates a person's ability on a 3-point scale indicating the extent to which they can perform a behaviour without help or reminders, with responses ranging from 'Never' to 'Usually or most of the time.' Normative scores (i.e., scores that compare a person to same-aged peers without a disability) are generated via a digital scoring platform.

Pat Mirenda, February 16, 2022

How Accurate Are These Measures?

Both the PEDI-CAT and the Vineland-3 are widely used and, in general, are reliable and valid measures of adaptive functioning. However, scores obtained via parent report are known to be less reliable than those obtained via a structured interview, as they require parental reading ability to understand the questions and manage the rating scale. Further inaccuracies may arise when parents may either deliberately or sub-consciously over-emphasize difficulties in an attempt to qualify for more services, or under-emphasize difficulties in an attempt to deny problems, perhaps because of cultural biases.

In addition, both measures have been found to have what is called a "floor effect," at least in some cases. This means that, in some domains, a measure is less accurate because there are insufficient items at the lower end (i.e., the "floor") of the measure. For example, in a PEDI-CAT study of children and young adults (ages 4.4-23.0) with spinal muscular atrophy (SMA), floor effects were found for individuals with SMA type I in the Daily Activities domain and those with SMA types I and II in the Mobility domain (Pasternak et al., 2016). When used to assess individuals with Fragile X syndrome (FXS; ages 1.6-50.9 years), floor effects were evident for between 25% to 50% of participants on both the PEDI-CAT and the Vineland-3, depending on the domain assessed (Cordeiro et al., 2020). Similarly, in a study of preschoolers (ages 24-63 months), 84% of whom were diagnosed with autism spectrum disorder (ASD), a floor effect was found for Daily Living Skills and Communication domains on the Vineland-3 (Milne et al., 2019), but not on the PEDI-CAT. No studies to date have examined this issue for individuals with other neurodevelopmental conditions (e.g., Down syndrome, FASD), but it is likely that floor effects are present for other conditions as well. **The result of a floor effect is that the scores obtained for young children and for individuals with more significant functional needs may result in an over-estimation of their ability and an under-estimation of their support needs.**

How Are Scores Used to Determine Service Eligibility?

Neither of the two measures results in an automatic "cut-off score" that in and of itself indicates service eligibility and/or support needs. Thus, it will be up to (in this case) MCFD to determine how the total and/or domain scores from these measures will be used for each purpose. One approach to this issue was documented in the only published study on this topic to date – the Milne et al. (2019) study that was referred to previously. It included 75 preschoolers from an agency in Australia, 84% of whom had a diagnosis of ASD. In Australia, assessment of adaptive functional skills and support needs has recently become the means by which eligibility for intervention funding is determined through the National Disability Insurance scheme (NDIS). The PEDI-CAT and/or the Vineland-3 are used to determine eligibility and support needs through the NDIS.

In Milne et al., eligibility for support was indicated by a score more than two "standard deviations" below the average score on any domain or subscale of the Vineland-3 or the PEDI-CAT. A standard deviation (SD), as the term implies, it is the standard (or typical) amount of deviation (or distance) from an average score. On the Vineland-3, the average score is 100 and the SD is 15, meaning that scores are distributed in groups of 15. So, one SD below the average encompasses scores from 85 to 100 (100 minus 15) and two SDs below the average encompasses scores from 70 to 100 (100 minus 15, minus 15). Thus, in Milne et al., children whose scores on the Vineland-3 were less than 70 were eligible for support; this applied to 72 out of 75 children (96%). On the PEDI-CAT, the average score is 50 and the SD is 10; thus, two SDs below the average is a score of 30 (50 minus 10, minus 10). In Milne et al., 56 out of 75 children (75%) whose scores were below 30 were eligible for support. So, **the Vineland-3 identified significantly more children as eligible for support, compared to the PEDI-CAT.**

Pat Mirenda, February 16, 2022

In practical terms, use of the "two SDs below average" rule meant that **children with fewer skill deficits, as measured by one more both of the assessment tools, were not eligible for support**. Using the Vineland-3, three children were ineligible, but using the PEDI-CAT, 19 children were ineligible. Of course, MCFD might decide to use a different rule/formula to determine service eligibility; but even if this is the case, it seems clear than the Vineland-3 and the PEDI-CAT do not yield similar eligibility outcomes.

How Are Scores Used to Determine Service Support Needs?

The "two SDs below average" rule was also used to determine the extent of support needs in Milne et al. (2019). Children whose scores were between 56-70 on the Vineland or 21-30 on the PEDI-CAT were deemed in need of *support*. Children whose scores were 41-55 on the Vineland or 11-20 on the PEDI-CAT were deemed in need of *substantial support*. Finally, children whose scores were 40 or less on the Vineland or 10 or less on the PEDI-CAT were deemed in need of *very substantial support*. In the end, **significantly more children were identified as needing higher levels of support across domains using the Vineland-3 compared to the PEDI-CAT.** Again, MCFD might decide to use a different formula to determine service support needs but again, the supports provided are likely to be different, depending on the measure that is used.

Questions That Remain

Regarding support eligibility, application of the "two SD below average" rule will mean that children with fewer skill deficits (i.e., scores that are above 70 on the Vineland-3 and/or above 30 on the PEDI-CAT) are likely to be deemed ineligible for support. This could disadvantage children with, for example, FASD, dyslexia/learning disability, and ADHD, in addition to children who are mildly affected by ASD, cerebral palsy, Down syndrome, and other neurodevelopmental conditions. However, no information is currently available about how scores will be used, and many questions remain unanswered.

- Will the "two SDs below average" rule be in place to determine eligibility? If not, how will the scores be used for this purpose?
- Which of the two measures will be used – the Vineland-3, which is likely to identify more children as eligible, or the PEDI-CAT, which is likely to disqualify more children? Or, will a formula be put in place to combine the two scores; if so, what is the formula?

Regarding service support needs,

- The likelihood of floor effects both measures means that scores obtained for young children and for individuals with more significant functional needs may result in an over-estimation of their ability and an under-estimation of their support needs. How will this be accounted for?
- Will the "two SDs below average" rule be in place to determine service support needs? If not, how will the scores be used for this purpose?
- Which of the two measures will be used for this purpose – the Vineland-3, which is likely to identify more children with high service needs, or the PEDI-CAT, which is likely to identify fewer children with high service needs?

In addition:

- How will the assessment for eligibility and service needs be completed by caregivers whose primary language (e.g., Mandarin, Cantonese, Punjabi, Tagalog) is not available in translated versions of the two measures, or by caregivers who are unable to read and/or write? Although both measures can be administered via interview by a professional who has a Level B test qualification, this requires a **graduate degree** in psychology or a related discipline (e.g., counseling, education, human resources, social work) **and completion of graduate-level coursework** in psychological testing or measurement; OR **equivalent training focused on psychological testing or measurement from a reputable organization**. In most cases, CYSN workers and their equivalents do not meet these qualifications.
- How often will eligibility and service support needs be re-assessed? If a child improves, will supports be terminated and if so, when and how?

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