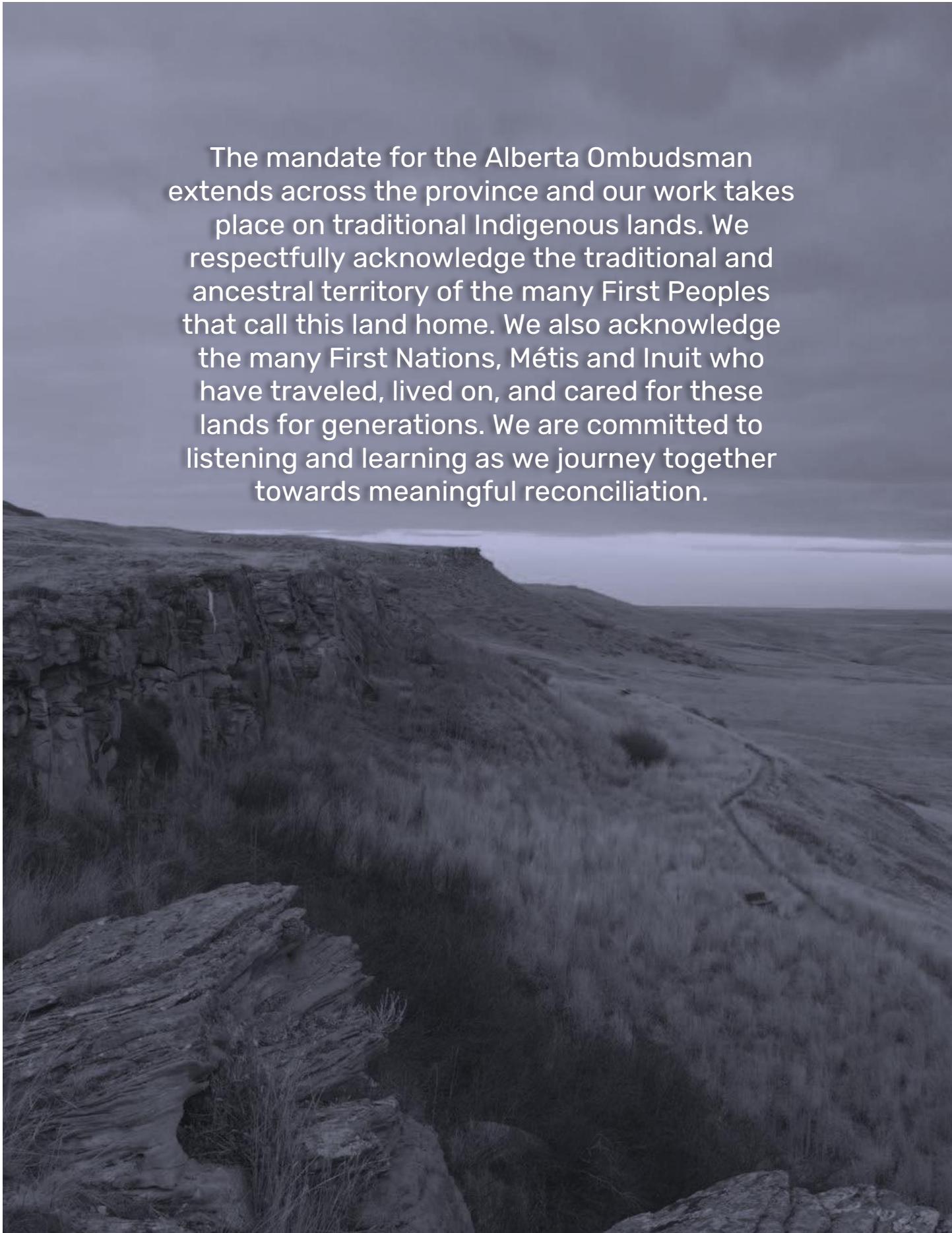




DENIED BY DESIGN

Inadequate Regulation Impacts
Benefit Access for People with
Developmental Disabilities

The background of the page is a dark, monochromatic photograph of a landscape. It shows a rocky cliffside in the foreground on the left, overlooking a valley. A winding road or path is visible in the distance, with a small vehicle parked on it. The sky is overcast and grey. The text is overlaid on the upper portion of the image.

The mandate for the Alberta Ombudsman extends across the province and our work takes place on traditional Indigenous lands. We respectfully acknowledge the traditional and ancestral territory of the many First Peoples that call this land home. We also acknowledge the many First Nations, Métis and Inuit who have traveled, lived on, and cared for these lands for generations. We are committed to listening and learning as we journey together towards meaningful reconciliation.

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OMBUDSMAN'S MESSAGE



In Alberta, the government's Persons with Developmental Disabilities (PDD) program is available to adults with disabilities seeking services for support in the home, workplace and social environments based on their individual needs. In order to access services, individuals are assessed against a list of criteria to determine eligibility for the program.

This investigation began when my office received a complaint from a mother acting on behalf of her son, Evan Zenari, who was denied PDD benefits. Evan was born with developmental disabilities, including autism spectrum disorder, and up

until his 18th birthday he had received support through the government's Family Support for Children with Disabilities program.

The PDD program determined Evan was ineligible for benefits, stating his Full Scale Intelligence Quotient (FSIQ or IQ) was too high to meet the criteria. When Evan's mother brought the matter forward for appeal, pointing out that the IQ score was not indicative of his ability to function in a real-world setting, the Citizens Appeal Panel effectively agreed with her. Further, the Panel concluded the IQ score was not accurate and without a valid score to rely on, the Panel concluded it was unable to decide eligibility. Seeing no jurisdictional way forward, and no recourse for any other option, the Panel was left unable to confirm, reverse or vary the PDD program's decision to deny benefits.

My office's role is to review the administrative fairness of processes and decisions being made in the public sector. In reviewing the evidence, I am concerned by the systemic issues that have surfaced through this case. Problems related to the criteria for assessing intellectual capacity in the PDD program's governing regulation may specifically affect individuals with IQ scores not indicative of their intellectual capacity, such as those with autism spectrum disorder.

While this investigation report focuses on the events one family experienced, the Court of Queen's Bench identified the same issue over 10 years ago. The case held that the *Developmental Disabilities Regulation* (the Regulation) limits how PDD applicants may be assessed if they are unable to produce a valid and reliable FSIQ score, which leads to outcomes incongruent with the aims of the *Persons with Developmental Disabilities Services Act*. In the 2013 Court decision, Justice Ouellette noted that this limitation " ...is a clear indication that the current

Legislation is flawed." Moreover, the Court pointed out it was never the intention of the legislature for an IQ score to be the sole determinant for proving eligibility.

To gain insights from subject-matter experts on the use of psychological assessments for determining eligibility, my investigators contacted the College of Alberta Psychologists. In the report, we include the College's perspective. They cautioned against relying on the FSIQ score alone for use in psychological assessments. They emphasized the importance of considering adaptive functioning alongside intellectual abilities when assessing pervasive developmental disorders and advised that any program eligibility criteria should align with current scientific data.

The investigation found the Seniors, Community and Social Services (the Department) has reviewed the Regulation three times since the Court rendered its decision, yet no amendments have been made. As a result, I found section 3 of the Regulation to be unreasonable and improperly discriminatory. To address the issues identified in this investigation, I shared two recommendations with the Department. The goal is to improve processes for future PDD program applicants, as well as resolve the unfairness experienced by Evan.

It is crucial to have supports that allow people with disabilities to be fully included in community life. When people with disabilities have access to services that are based on equitable opportunity, funding, and access to resources, they can continue to lead fulfilling lives and contribute in more meaningful ways. This inclusive approach benefits everyone by bringing together unique perspectives, breaking down stereotypes, and leading to more inclusive and compassionate cultures.

At the time of the writing of this report, the Department has yet to fully accept and implement my recommendations. On a hopeful note, the Regulation is due for review and renewal by September 2024. I strongly encourage the Department to take immediate steps and accept my recommendations. Until the Department takes action, potential remains for others to experience similar barriers to accessing PDD program services.

I would like to extend sincere thanks to my investigative team and to the Zenari family for trusting us with their complaint and for their dedication in seeking a fair process for their son.



Kevin Brezinski

WHAT HAPPENED

Janice Zenari is the mother and legal guardian of Evan. The family received support from another government program, Family Support for Children with Disabilities, while Evan was a child. Prior to his 18th birthday, his parents applied to the PDD program on Evan's behalf. In addition, Evan underwent a capacity assessment, which determined he was incapable of making any major life or financial decisions for himself. As a result, Evan's parents will remain his legal guardians throughout adulthood.



Material republished with the express permission of Janice and Evan Zenari.

“Evan’s mental health and difficulty finding a job are made worse by a lack of support and services. This makes it even harder for him to start his adult life on strong footing, and as a parent, I’m really worried about how he’ll cope without government services, especially when I’m no longer around to support him.”

- Janice Zenari, Evan’s mother

As part of the application for PDD, a psychologist assessed Evan to determine his IQ score, which she concluded was 79. However, she noted it was not the best indication of his overall level of functioning, due to the wide range between his lowest and highest scores. The psychologist opined that Evan’s IQ score was an overestimation of his abilities in a real-world setting and that he would require support(s) and accommodation(s) to aid his daily living.

The PDD program denied Evan’s application because his IQ score was higher than 70. According to the Regulation, anyone falling above the threshold of 70 is ineligible. However, Janice believed the decision was unfair and appealed it to the Panel. The Panel heard submissions from Evan’s family and the psychologist who assessed him, as well as from the PDD program’s internal psychologist. Based on the information presented, the Panel determined that Evan’s IQ score “...*is not accurate or valid and that the Panel cannot rely on it.*”¹ Despite finding Evan’s IQ score could not be relied upon, the Panel decided it was unable to change the PDD program’s decision because of the **2013 Court decision.**² The 2013 Court decision involved similar circumstances to Evan’s and held that the Regulation’s reference to IQ scores limits the program’s ability to properly assess applicants, particularly

¹ Persons with Developmental Disabilities Citizen’s Appeal Panel Decision letter, signed February 25, 2022

² *DH v Persons with Developmental Disabilities, South Region Community Board, 2013 ABQB 197*

when an IQ score is invalid or unreliable. According to the Court, these limitations resulted in “flawed” legislation.

Evan was in a no-win situation. While the Panel agreed that his IQ score was not a valid assessment of his intellectual capacity, the Panel also decided that existing legislation prevented it from using other means to assess Evan’s disabilities. Consequently, the Panel determined it could not make a decision. Because the Panel made “*no decision*”, the PDD program refused to reconsider Evan’s application even though the Panel found his IQ score to be invalid.

Believing the Panel’s decision to be unfair, Janice asked the Ombudsman’s office to review the decision denying her son’s application. In her complaint, Janice explained that:

- Despite finding Evan’s IQ score was not valid, the Panel determined it could not change the PDD program’s decision. This was unfair as she felt it left Evan without the supports he needs.
- The intent of the PDD program’s legislation is to assist people with developmental disabilities. She argued the PDD program’s eligibility requirements are prejudicial and contradictory to the spirit of the legislation.
- It has been years since the Court pointed out the limitations of the PDD program’s legislation, and, despite this, nothing has been done to correct it. Because of this, she believes the government is refusing to acknowledge its legislation is discriminatory against a vulnerable population.

WHY IT MATTERS

The current Regulation unfairly affects a vulnerable population and those that care for them. Sometimes, fairness requires that legislation be adapted to ensure every Albertan’s needs are met and they have access to a fair process. Updating the Regulation would help prevent future applicants, like Evan, from falling through the cracks and being left without the support they need.

THE 2013 COURT DECISION

The Court decision cited by the Panel is over 10 years old and pointed out problems in the PDD program's enabling legislation.

Given the decision of the Court and evidence uncovered by our investigation, the Ombudsman agreed that the PDD program's over-reliance on IQ scores to determine Evan's eligibility for benefits was unfair. Our investigation also found that, in the 10 years since the Court's decision, the Regulation had been reviewed three times and the Department neglected to make any changes to address the limitations identified by the Court.

In July 2023, the Ombudsman recommended the Department take steps towards changing the Regulation in accordance with the Court's decision:

specifically, the assessment of an individual's intellectual capacity should be aligned with current psychological standards, particularly when there is no valid or reliable IQ score. The Ombudsman also recommended the PDD program reassess Evan's intellectual capacity and reconsider his application for benefits.

Acceptance of these recommendations would not only help Evan but other vulnerable Albertans who are in a similar situation.

DH v Persons with Developmental Disabilities, South Region Community Board

The subject of this case is an Appeal Panel's decision to uphold the Department's decision to deny an applicant to the PDD program based on her FSIQ score. In it, Justice Ouellette determined an Appeal Panel cannot make an eligibility decision based on an FSIQ score that is not reliable or accurate:

"If the legislature had intended that the sole determinant regarding eligibility was the FSIQ score without more, than they would not have had to make any reference to the mandatory application of the guidelines and the Control and Use of Tests by Psychologists... If the legislature only intended blind reliance on a raw test score, there would have been no need for consideration to the specific assessment instruments strengths and limitations. Further, there would be no requirement that psychologists not only rely on one test but also other information of the particular individual to determine reliability and validity.

This in fact is a clear indication that the current Legislation is flawed." (paras 43-44)

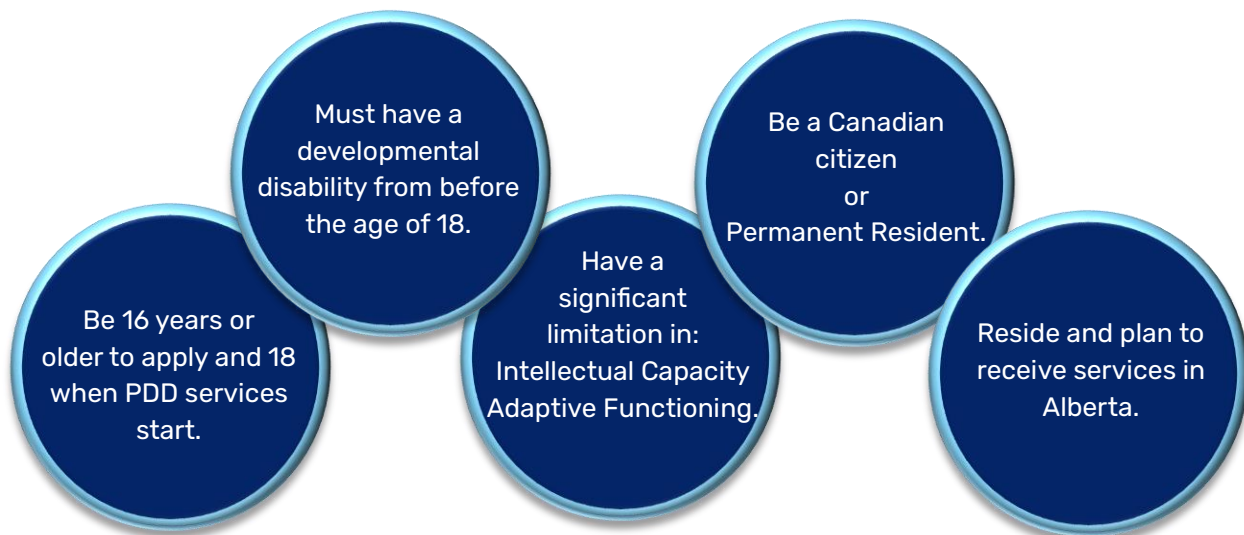
WHAT IS THE PDD PROGRAM?

The PDD program is a government benefit program administered by the Seniors, Community and Social Services department. The PDD program assists adults with developmental disabilities to plan, coordinate, and access services to live as independently as possible in their communities.

It is important to note that the PDD program does not provide income in the form of a regular financial benefit. Instead, the PDD program provides adults with individualized supports and services to aid in daily living. This may include employment supports, respite services to give full-time caregivers a break, or specialized supports from experts to help with additional needs such as mental health or behavioural issues. Many individuals who receive benefits through the PDD program may also access financial assistance through other government programs.

Albertans with developmental disabilities can apply for PDD benefits when they turn 16 and can begin receiving benefits when they are 18 years old. To be approved for benefits, applicants must show they meet the PDD program's eligibility criteria.

PDD PROGRAM ELIGIBILITY CRITERIA



WHAT THE INVESTIGATION FOUND

Initially, our investigation focused on the fairness of the decision to deny Evan PDD program benefits, but concerns regarding the fairness of the Regulation arose during the course of our investigation.

WHAT ARE THE RULES?

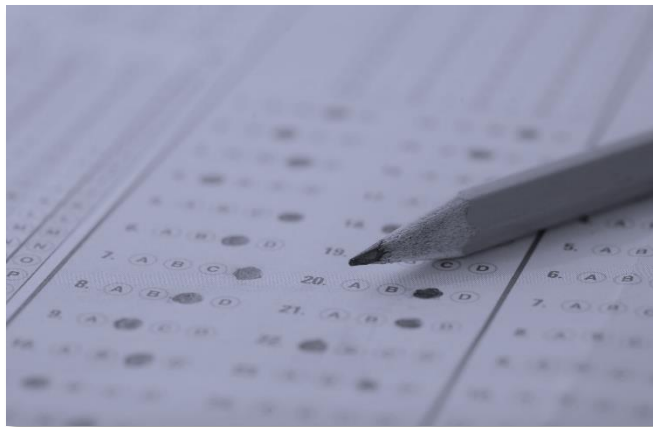
The criteria for PDD benefits are set out in the Regulation. According to the Regulation, there are only two options for assessing intellectual capacity:

1. Either an individual's IQ score is less than 70, or
2. They are unable to complete the IQ test at all.

DID THE PDD PROGRAM APPLY THE RULES?

From the outset of our investigation, it was evident that the PDD program's assessment of Evan's intellectual capability and, consequently, his entitlement to benefits was based, at least in part, on his IQ scores. The use of IQ scores is appropriate given the current wording of the legislation. In fact, according to the Regulation, IQ scores are the determining factor when assessing intellectual capacity.

The family was initially advised by the PDD program that Evan's application for benefits was being refused because his IQ score was too high. Janice appealed the program's decision, and the Appeal Panel found that Evan's IQ score was invalid.



Following the Panel's decision and in response to questions from our investigators, the PDD program advised it did not rely solely on Evan's IQ score to determine his eligibility for benefits. It explained its internal psychologist considered Evan's school records and his IQ test scores. Based on this information, the program decided that Evan did not have a significant limitation in intellectual capacity and was therefore ineligible for PDD benefits. The PDD program also advised that it was aware of the Panel's finding that Evan's IQ score was not accurate or valid; however, the Panel's finding did not impact its assessment of Evan's eligibility for the PDD program.

The PDD program's explanation as to how it assessed Evan's intellectual capacity is unsatisfactory. According to the Regulation, IQ scores play an important, if not determinative, role in assessing intellectual capacity. As such, in making its

decision, the PDD program either based its assessment on an invalid IQ score, or the IQ score played little or no role, and the program's assessment was based on factors that do not exist in the current Regulation (e.g., school records). The PDD program did not follow the rules set out in Regulation, and the Ombudsman found this to be unfair.

Given the current Regulation along with the Panel's finding that Evan's IQ score was invalid and could not be relied upon, the family's expectation that the PDD program would reassess his eligibility for benefits was reasonable.

IS THE LEGISLATION FAIR?

The 2013 Court decision found the Regulation to be "*flawed*" because it limited the PDD program's assessment of an applicant's eligibility for benefits when an IQ score is found to be invalid or unreliable. It has been over 10 years since the Court identified a flaw in the Regulation affecting the rights of vulnerable Albertans, yet the Department has not taken steps to remedy the situation. The Ombudsman found this inaction to be unreasonable and unfair to vulnerable Albertans and those who care for them.

Our investigators interviewed the College of Alberta Psychologists (CAP) to obtain an expert opinion on the PDD program's use of psychological assessments for determining eligibility. CAP's response included the following points and comments:

- Any over-reliance on FSIQ score for pervasive development disorders does not align with contemporary clinical interpretive practices. In particular, the DSM-5³ emphasizes the importance of adaptive functioning when assessing an individual for a pervasive development disorder.
- Adaptive functioning is extremely important when considering an individual's ability to function in a real-world environment.
- From CAP's perspective, any program eligibility criteria should align with current scientific data. This means that assessment of pervasive developmental disorders should include assessment of both intellectual and adaptive functioning.

"CAP is pleased, when requested, to provide guidance and advice in psychological matters and in the public interest. It is in this spirit that we are working with PDD officials and the Ombudsman's office to ensure that any use of psychological information is in the public interest."

³ The Diagnostic and Statistical Manual of Mental Disorders (DSM-5) is an authoritative guide to mental disorders widely used in much of the world.

FINDINGS AND RECOMMENDATIONS

As a result of our investigation, the Ombudsman communicated three findings and two recommendations to the Deputy Minister of the Department. The recommendations were aimed at improving the process for future PDD program applicants, as well as resolving the unfairness experienced by Evan and his family.

FINDING #1	FINDING #2
<p>The Regulation, as written, prevents the PDD program from considering other information about an applicant, such as school records. The PDD program did not have the authority to consider Evan’s school records in making a decision about his eligibility for benefits. Therefore, the PDD program’s process for assessing Evan’s eligibility was unfair.</p>	<p>The Panel’s decision contradicts the PDD program’s position that Evan’s IQ score is a valid indication of his intellectual capacity. Consequently, the PDD program’s inaction in response to the Panel’s finding was administratively unfair.</p>

FINDING #3
<p>If the Regulation is not updated, appeal panels will continue to be prevented from changing the PDD program’s decisions when the applicant’s IQ score is invalid. As a result, individuals with IQ scores, which do not represent their abilities in a real-world setting, may not have access to a meaningful appeal process. This may specifically impact vulnerable Albertans, such as those with autism spectrum disorder and fetal alcohol spectrum disorder (FASD). Therefore, the current Regulation is unreasonable and improperly discriminatory.</p>

RECOMMENDATION #1	RECOMMENDATION #2
<p>I recommend the PDD program work toward amending the Regulation to align with the current psychological standards for assessing intellectual capacity, as defined by the DSM-5. Given the significant impact on a vulnerable population of Albertans, the PDD program should put forth changes to the Regulation immediately and in any event, no later than the expiry of the Regulation on September 30, 2024.</p>	<p>I recommend the PDD program reconsider Evan’s application for PDD benefits on the basis that the Panel found his IQ score was not a valid indication of his intellectual capacity.</p>

THE PDD PROGRAM'S RESPONSE TO OUR RECOMMENDATIONS

The Deputy Minister responded to the Ombudsman's letter advising the Regulation is scheduled for review in 2024 and that the Ombudsman's findings will be considered. However, the Deputy Minister rejected the Ombudsman's recommendation to reconsider Evan's application for PDD benefits.

Given the importance of the findings and recommendations in this case, the Ombudsman pursued further discussion with the Department about the matter. However, Evan is now 21 years old and is still left without the support of PDD benefits after three years. Additionally, the potential remains for others to experience similar problems to accessing services. The Ombudsman will continue to work with the Department and remains committed to taking steps necessary for implementing our recommendations and monitoring much-needed improvements to Alberta's *Developmental Disabilities Regulation*.



If you have any questions about the Alberta Ombudsman, or wish to file a complaint with us, please get in touch.

Edmonton Office:

9925 - 109 Street NW, Suite 700
Edmonton, Alberta T5K 2J8
Phone: 780.427.2756

Calgary Office:

801 - 6 Avenue SW, Suite 2560
Calgary, Alberta T2P 3W2
Phone: 403.297.6185

Email: info@ombudsman.ab.ca

Website: www.ombudsman.ab.ca

Toll free: 1.888.455.2756

Social Media:

