



Policy Wise
for Children & Families

Fetal Alcohol Spectrum Disorder Cross-ministry results

Download the report at:
<https://policywise.com/initiatives/cydl/p2>

January 27th, 2017

FASD panel

Dr. Christine Werk

- Research scientist, PolicyWise for Children & Families

Dr. Darcy Fleming

- Team Lead, Performance Management, Ministry of Community and Social Services

Dr. Gail Andrew

- Clinician, Alberta Health Services

Janice Penner

- Manager, Disability Supports Program Development, Ministry of Community and Social Services



Fetal Alcohol Spectrum Disorder (FASD)

Data in our study

- Health diagnostic codes (emergency room, other ambulatory care, and hospitalizations)
- Family Support for Children with Disabilities (FSCD) service

Missing data

- Diagnosed before 2005/06 and no FSCD service
- Online reporting system
- Physician claims





Fetal Alcohol Spectrum Disorder (FASD)

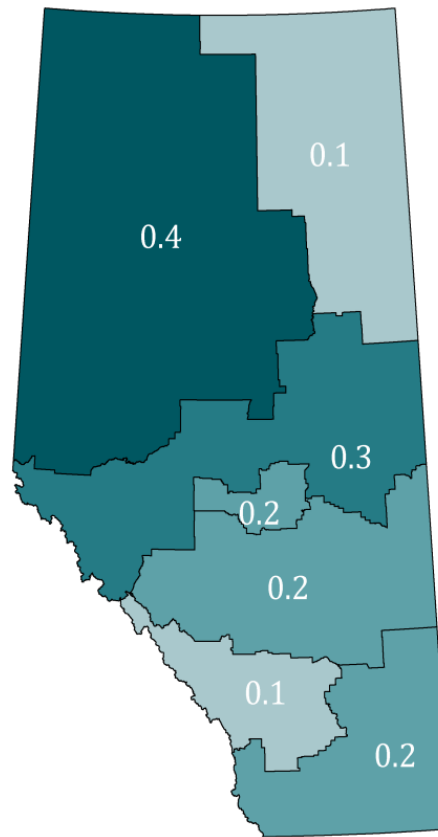
Context

- FASD at any point in the study for this report
- FASD services increased over the study years
- 3,025 with a diagnosis and/or an FASD-related FSCD service



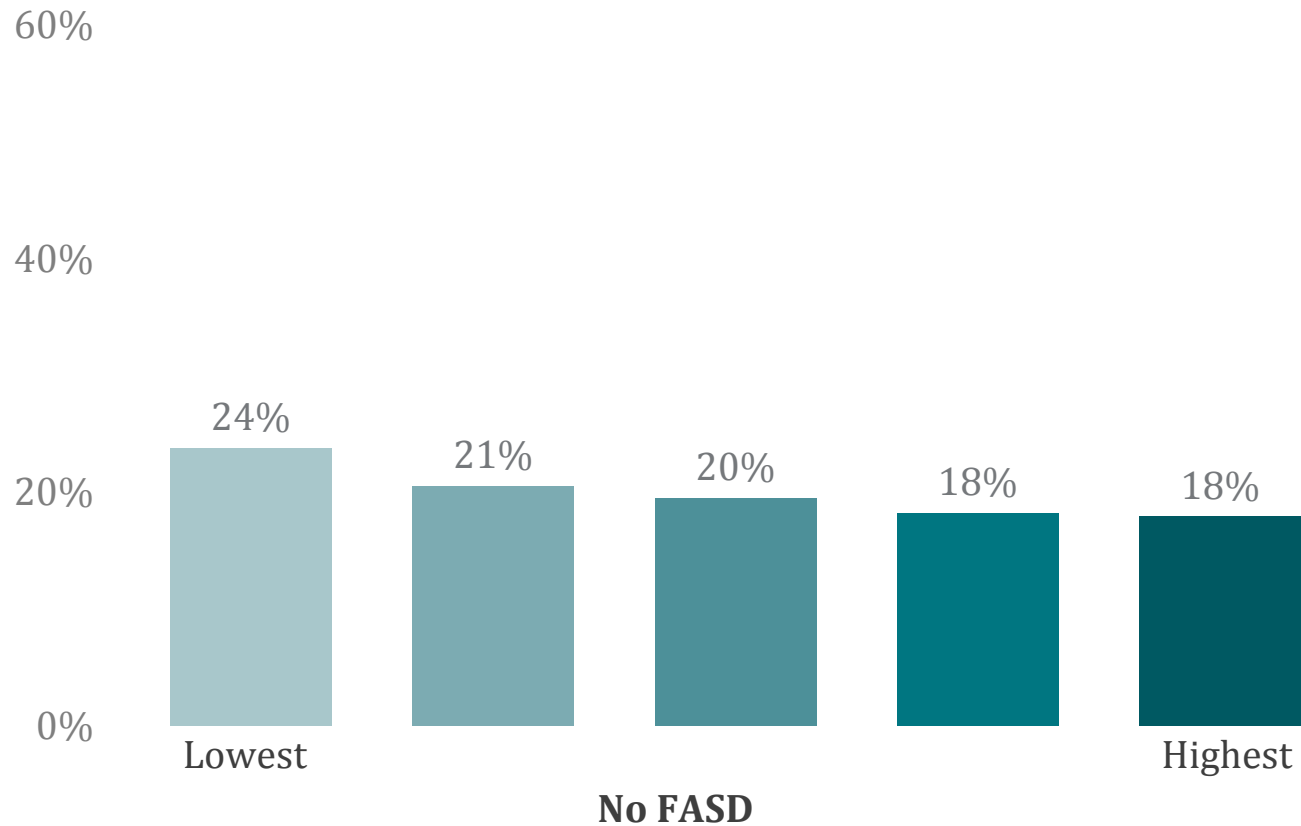
Human Services Region

Percentage of Albertans aged 0 to 25 with FASD by Human Services region



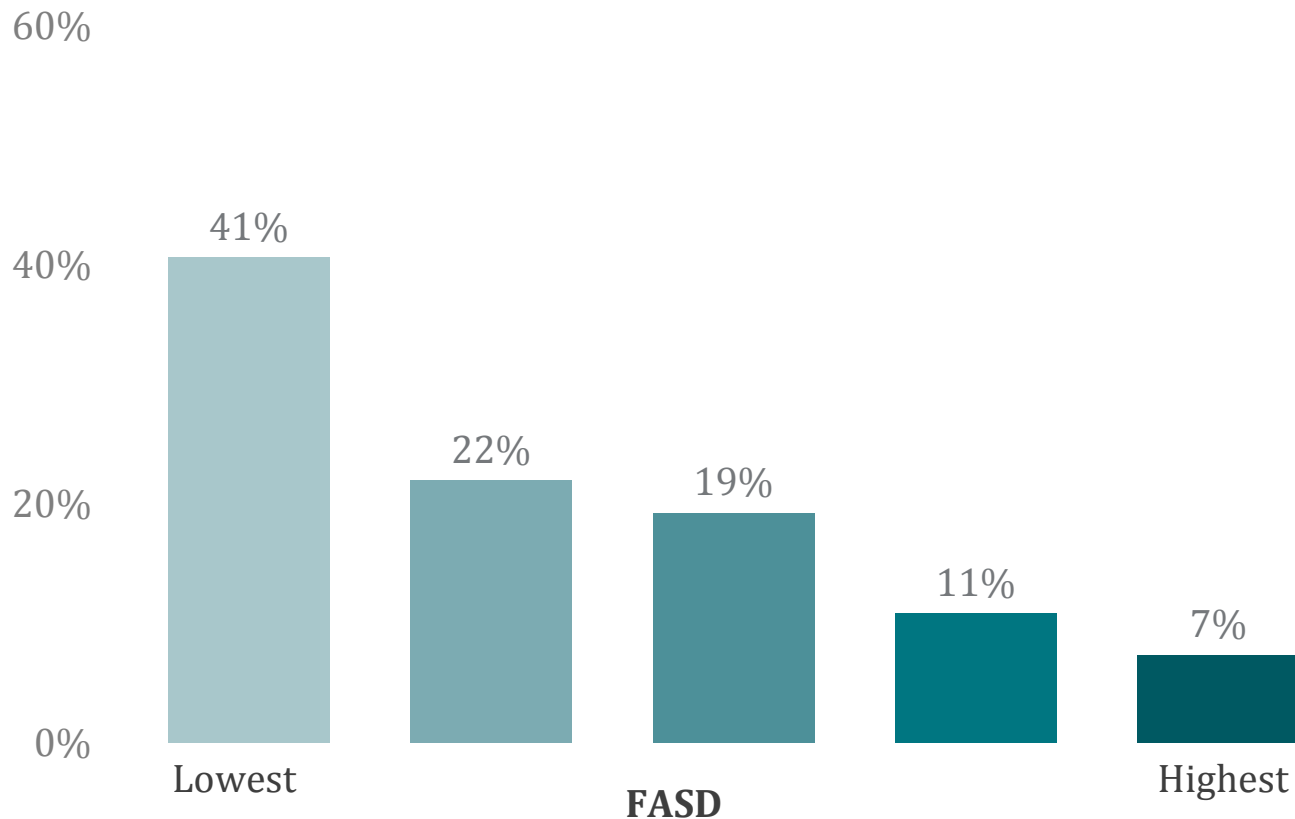
Socio-economic status

Percentage of Albertans aged 0 to 25 with no FASD by socio-economic status in 2010/11



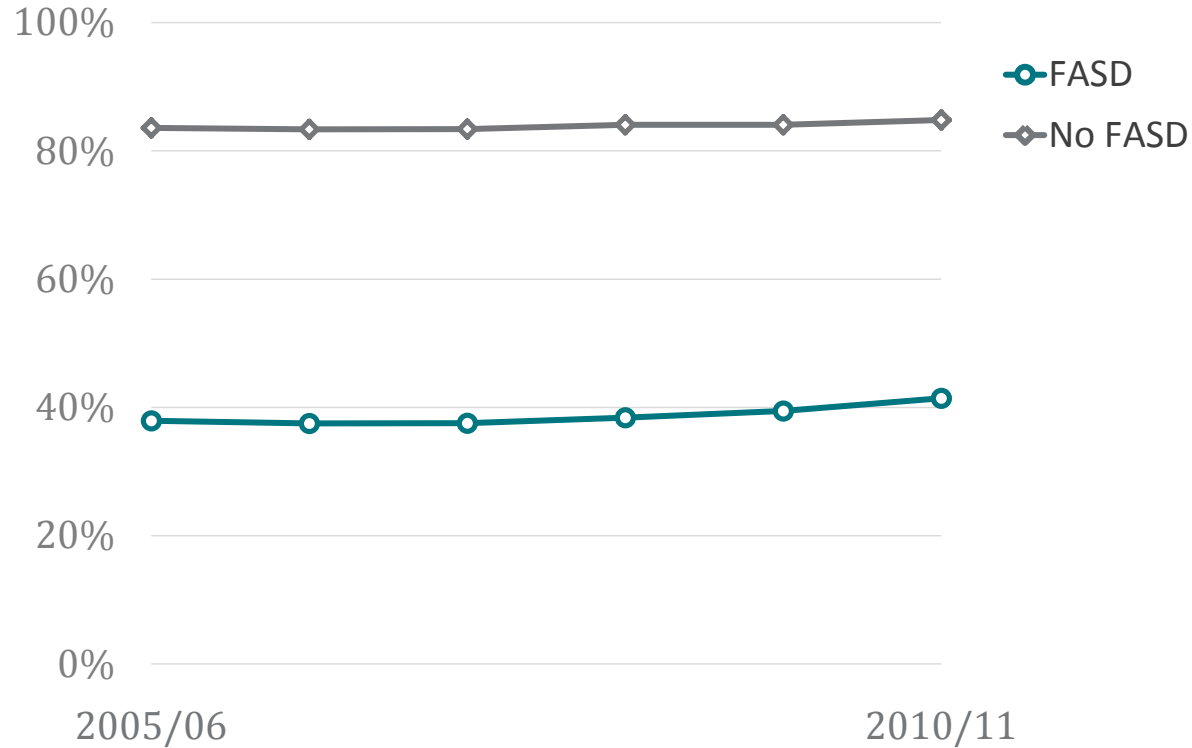
Socio-economic status

Percentage of Albertans aged 0 to 25 with FASD by socio-economic status in 2010/11



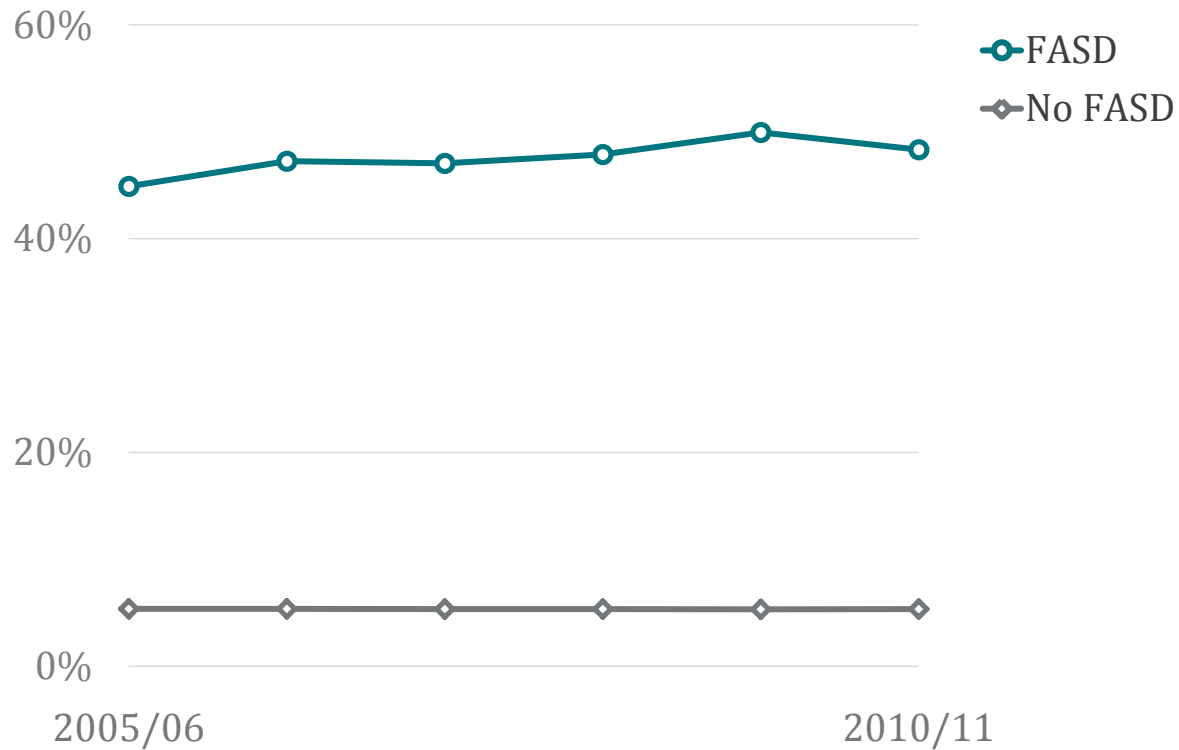
Educational achievement

Percentage of Albertans in grades 3 to 12 meeting or exceeding educational expectations over time



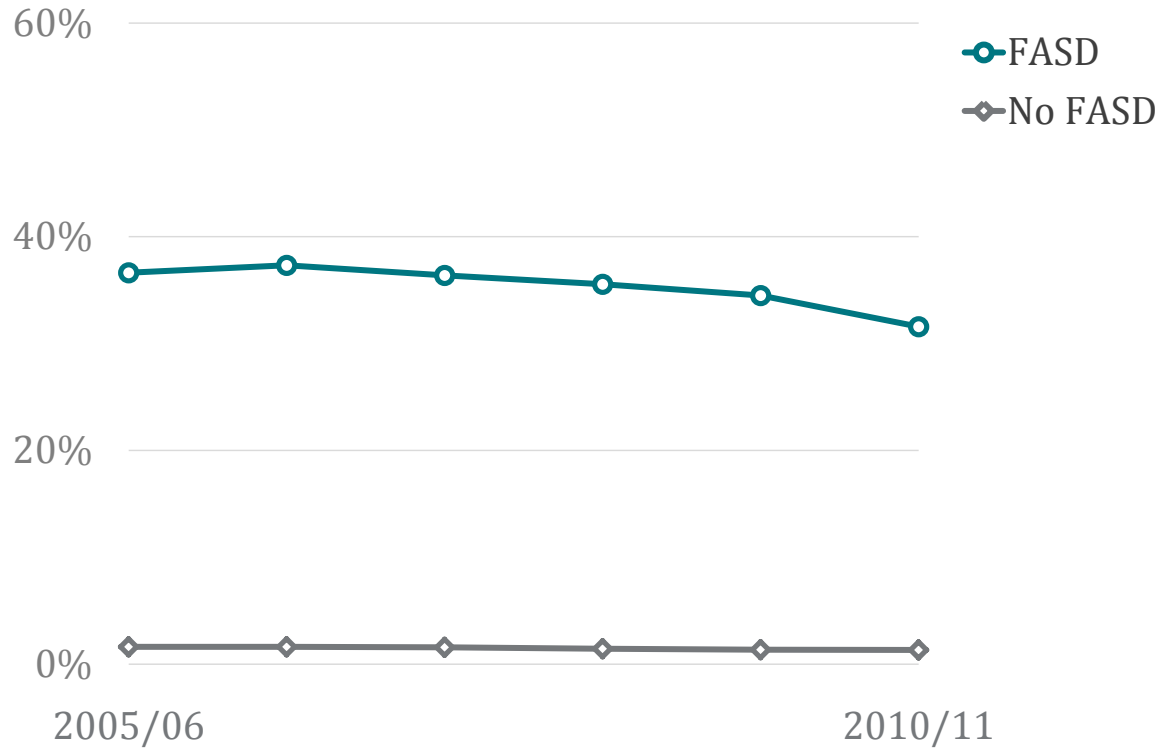
Mental health service

Percentage of Albertans aged 0 to 25 with mental health service use over time



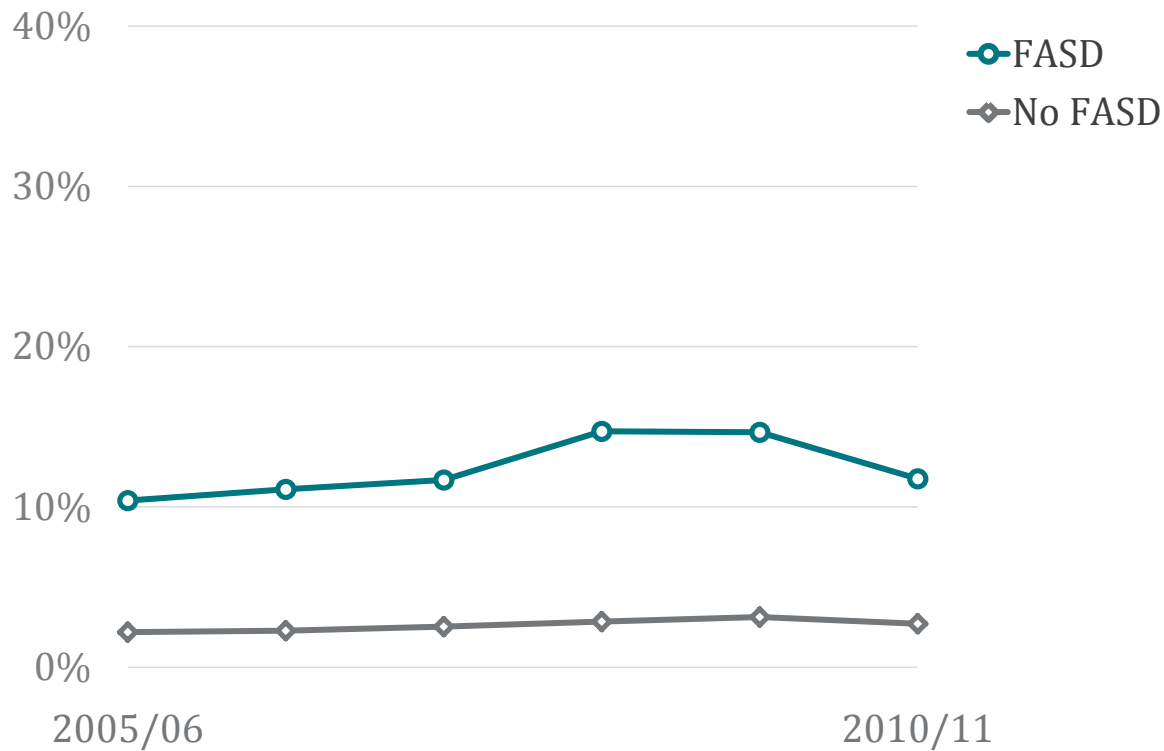
Child Intervention services

Percentage of Albertans aged 0 to 22 accessing Child Intervention services over time



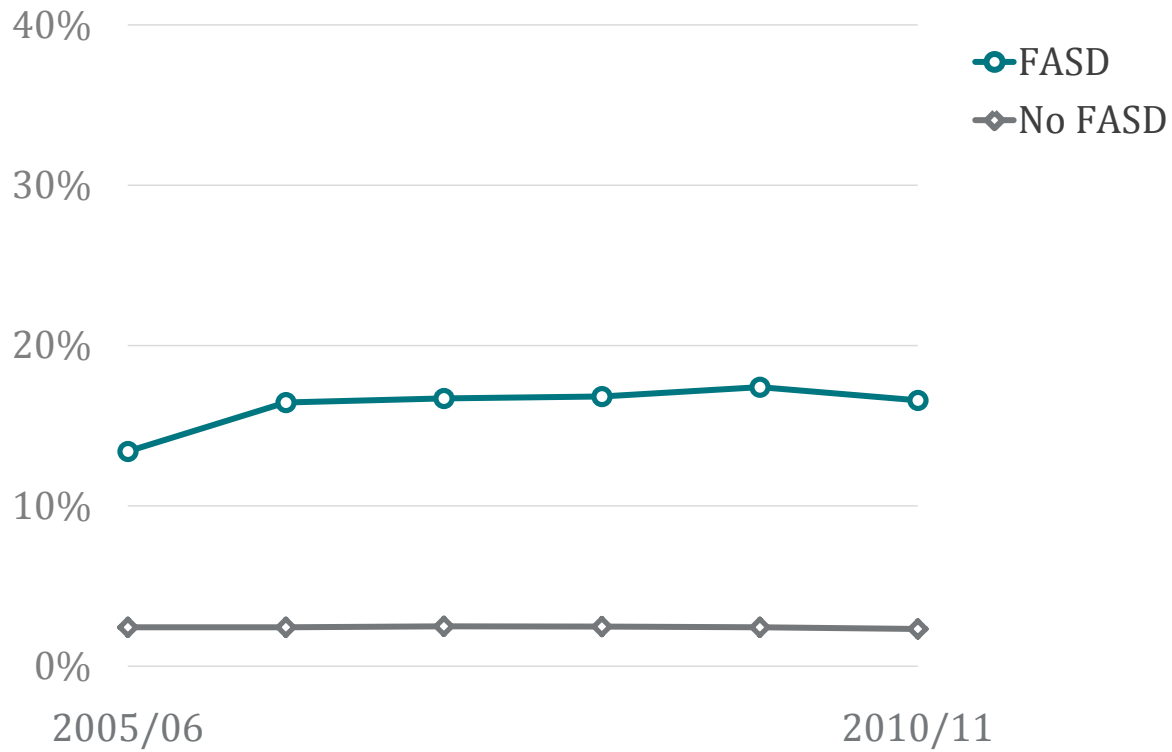
Income Support recipients

Percentage of Albertans aged 18 to 25 accessing income support services over time



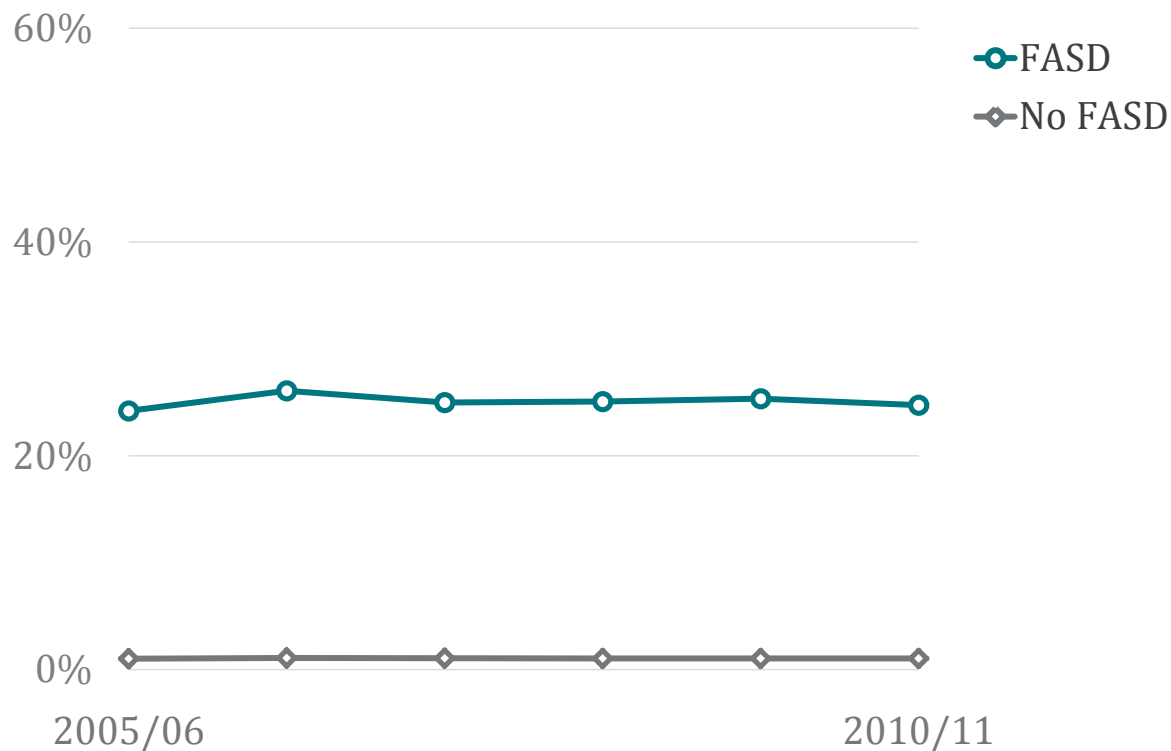
Criminal offences

Percentage of Albertans aged 12 to 25 with criminal offences over time



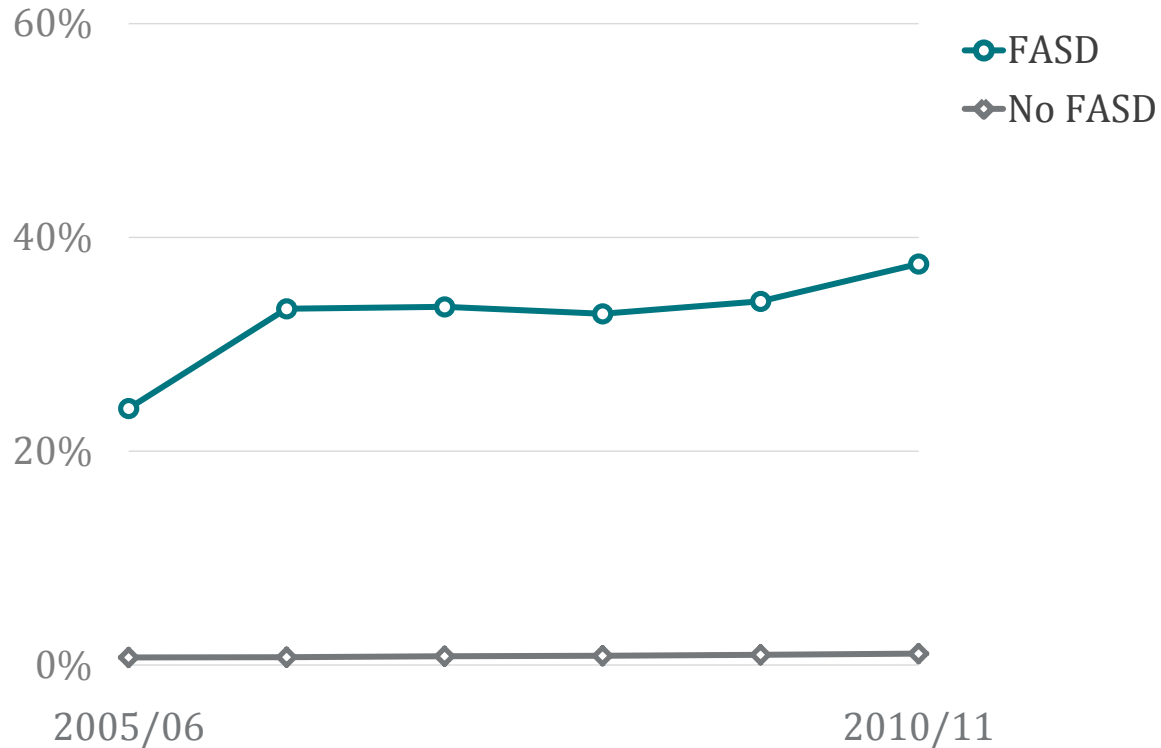
Family Support for Children with Disabilities

Percentage of Albertans aged 0 to 17 accessing Family Support for Children with Disabilities (FSCD) services over time



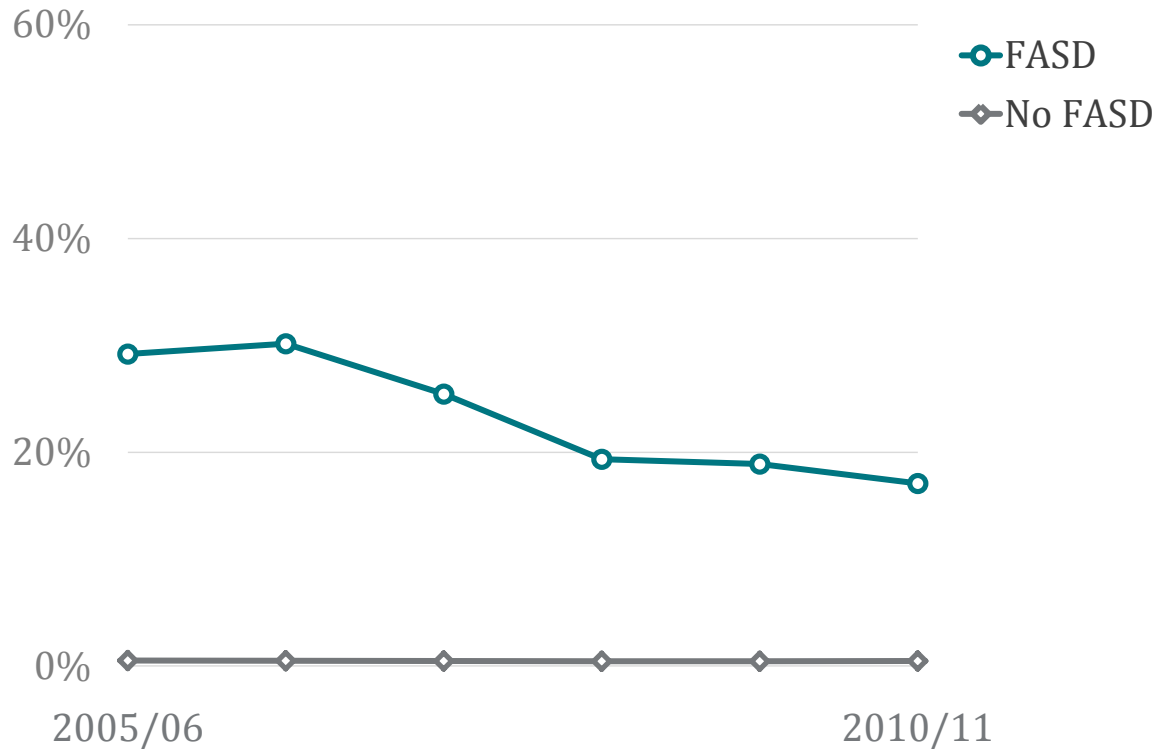
Assured Income for the Severely Handicapped

Percentage of Albertans aged 18 to 25 accessing Assured Income for the Severely Handicapped (AISH) services over time



Persons with Developmental Disabilities

Percentage of Albertans aged 18 to 25 accessing Persons with Developmental Disabilities (PDD) services over time



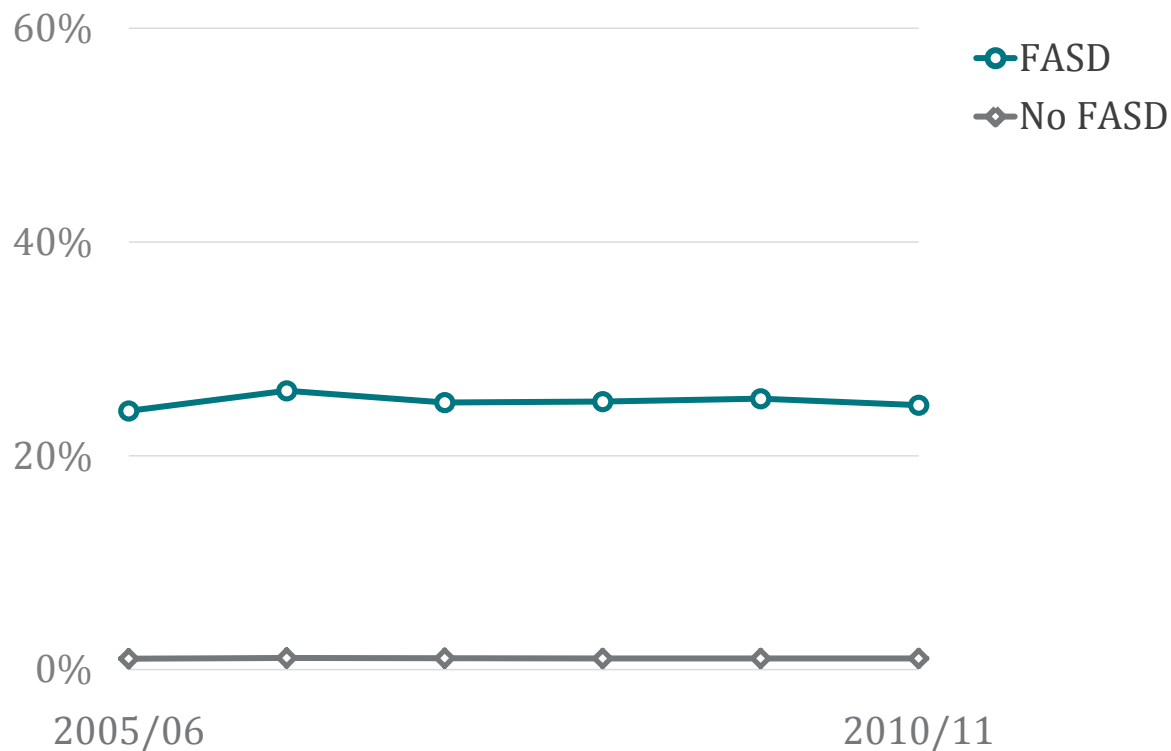
Next speaker



- Dr. Darcy Fleming

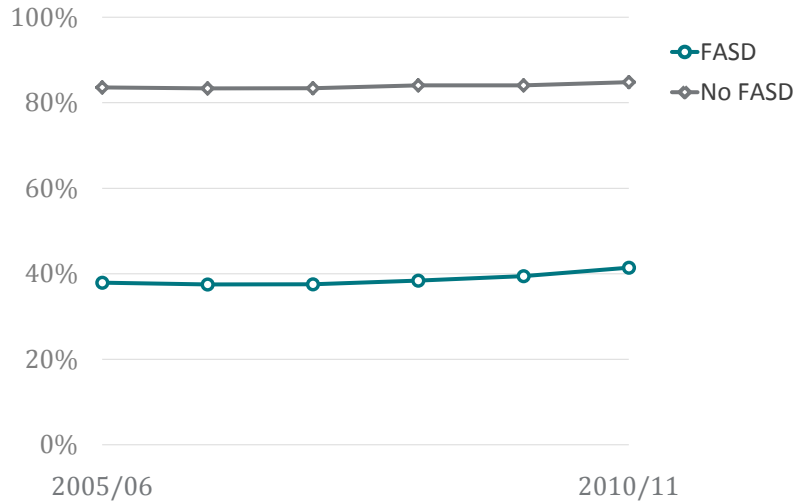
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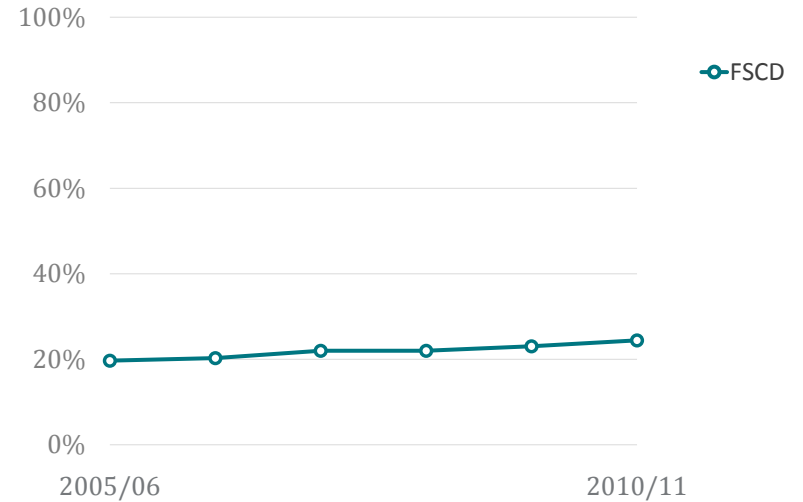


Educational achievement

Percentage of Albertans in grades 3 to 12 meeting or exceeding educational expectations over time

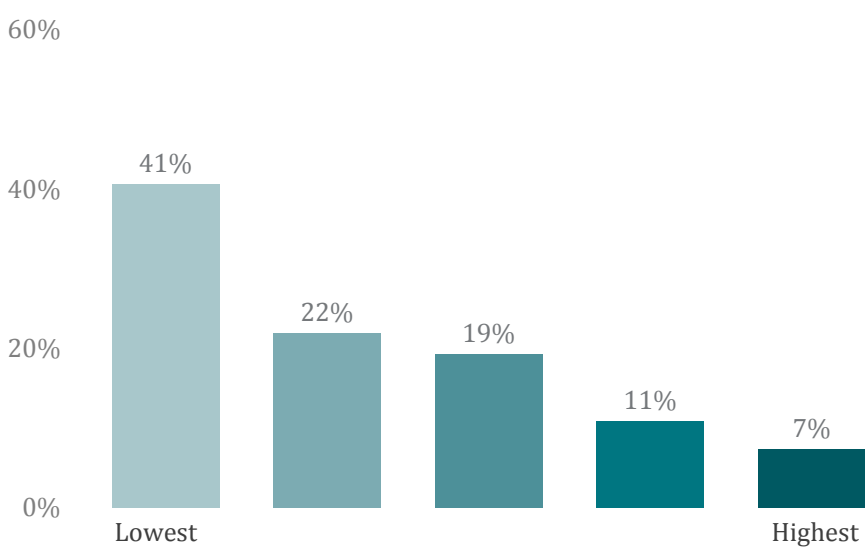


Percentage of Albertans in grades 3 to 12 meeting or exceeding educational expectations over time



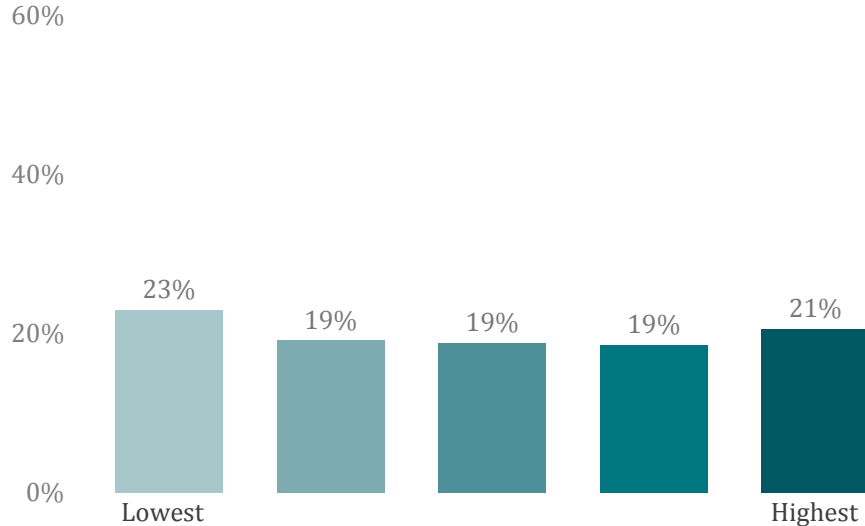
Socio-economic status

Percentage of Albertans aged 0 to 25 with FASD by socio-economic status in 2010/11



FASD

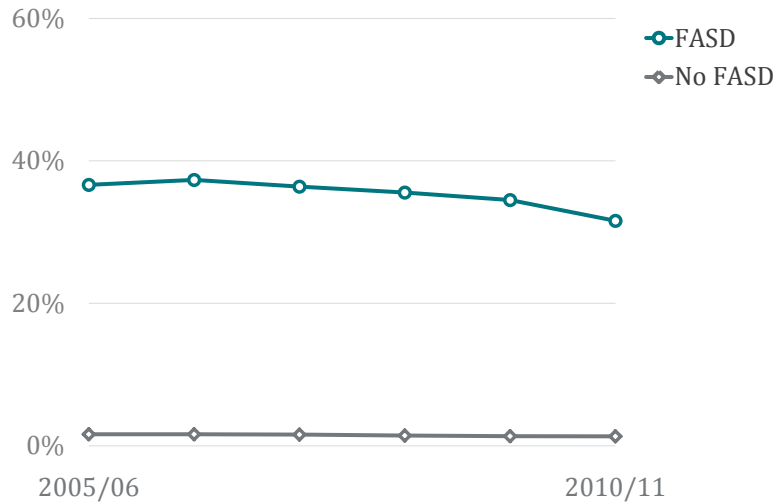
Percentage of Albertans aged 0 to 17 with FSCD services for developmental conditions/impairments by socio-economic status in 2010/11



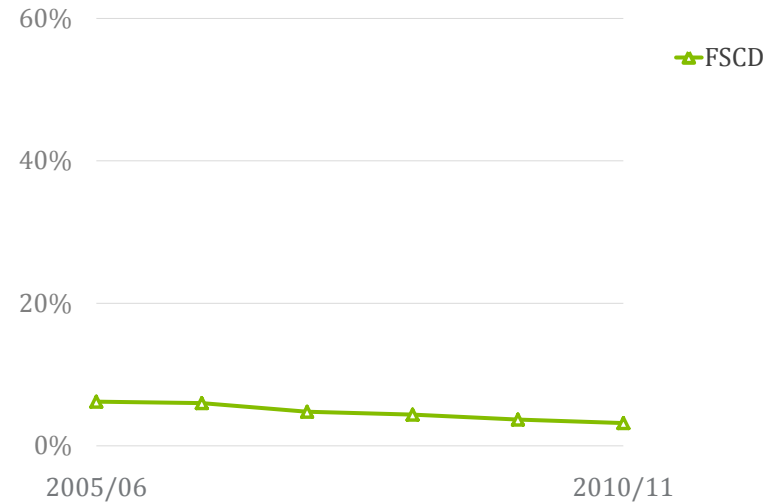
FSCD- Developmental conditions/impairments

Child Intervention services

Percentage of Albertans aged 0 to 22 accessing Child Intervention services over time



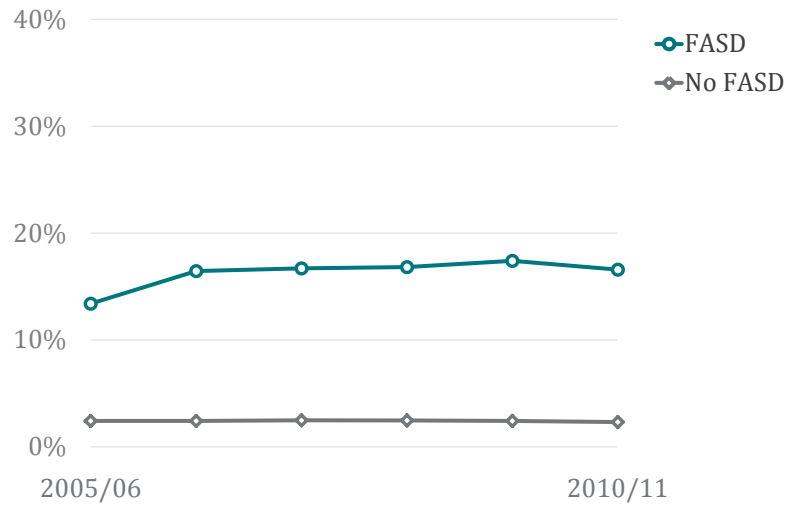
Percentage of Albertans aged 0 to 17 accessing Child Intervention services over time



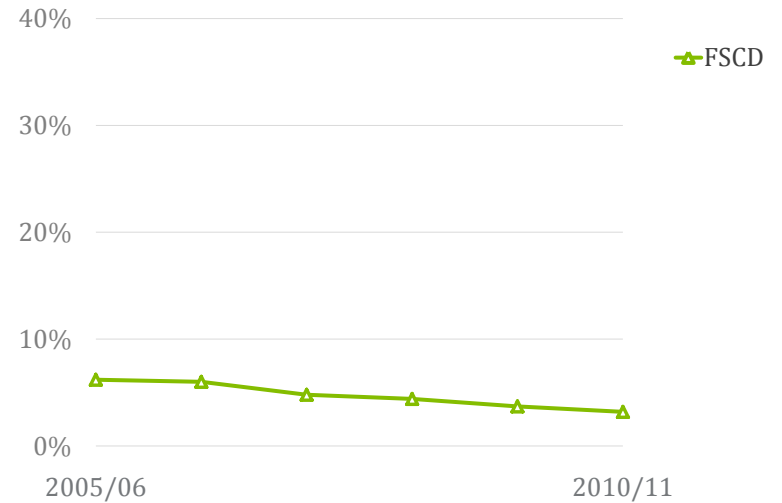


Offences

Percentage of Albertans aged 12 to 25 with criminal offences over time

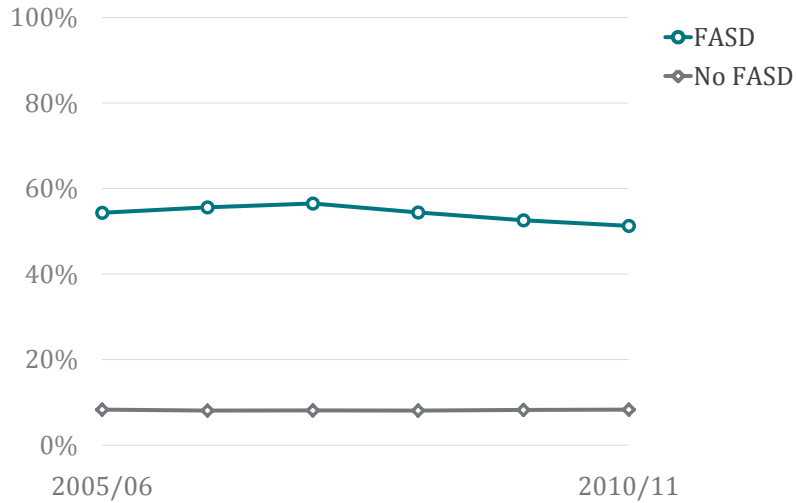


Percentage of Albertans aged 12 to 17 with criminal OR provincial offences over time

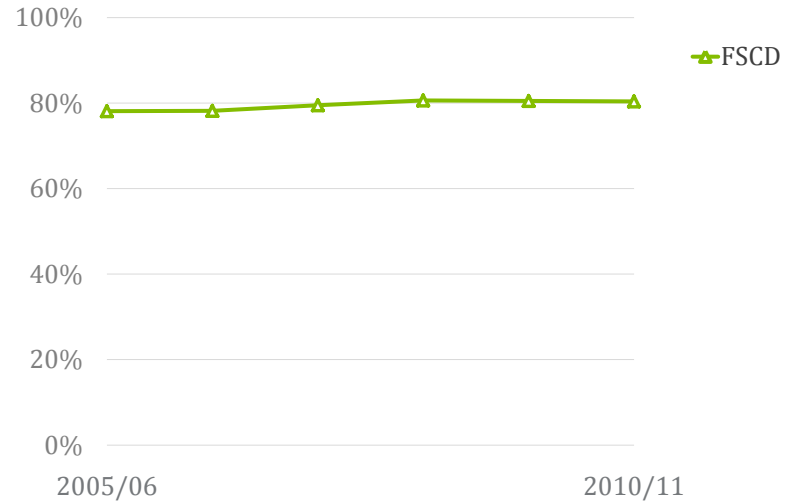


Students with special needs

Percentage of Albertan students aged 2.5 to 19 with special needs over time

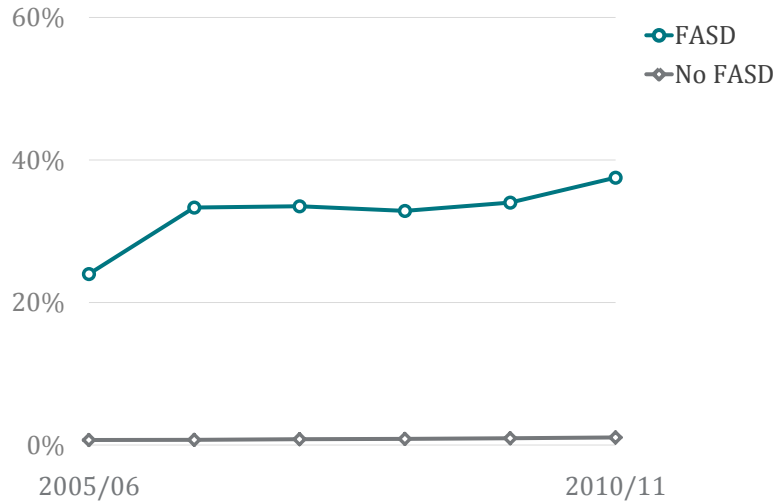


Percentage of Albertan students aged 2.5 to 17 with special needs over time

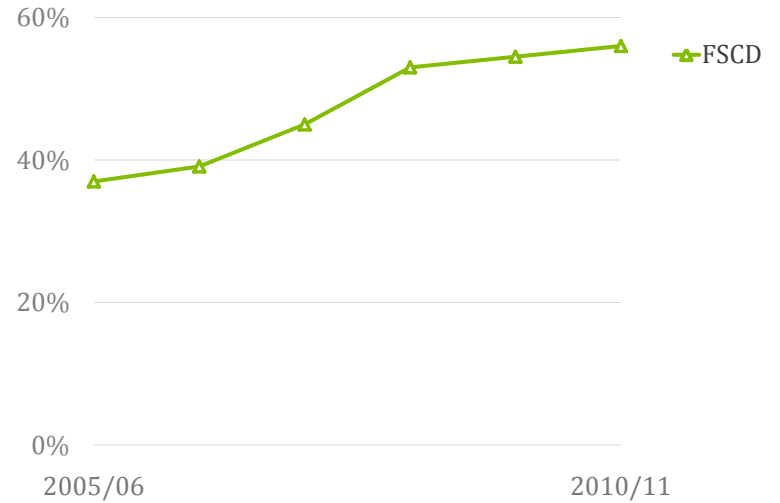


Assured Income for the Severely Handicapped

Percentage of Albertans aged 18 to 25 accessing Assured Income for the Severely Handicapped (AISH) services over time

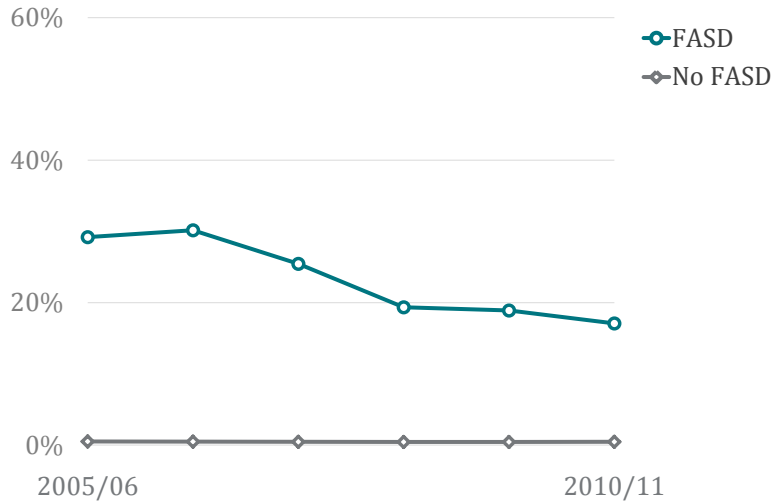


Percentage of Albertans aged 18 accessing Assured Income for the Severely Handicapped (AISH) services over time

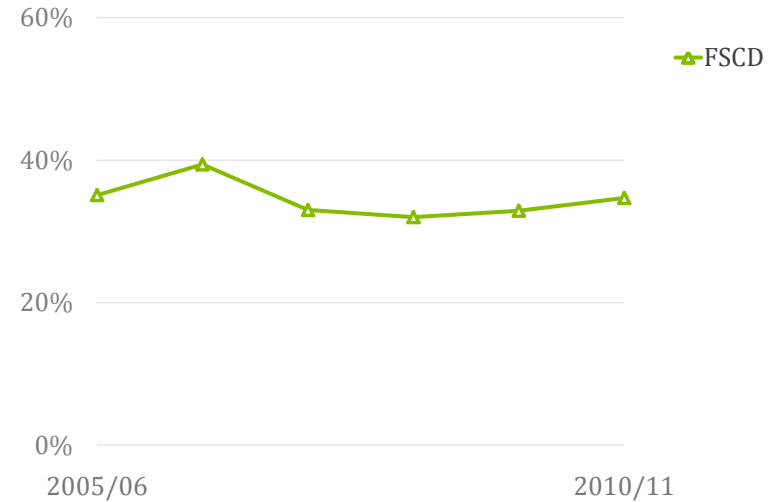


Persons with Developmental Disabilities

Percentage of Albertans aged 18 to 25 accessing Persons with Developmental Disabilities (PDD) services over time



Percentage of Albertans aged 18 accessing Persons with Developmental Disabilities (PDD) services over time



Clinical Expert Perspective
Dr. Gail Andrew
Medical Director Glenrose FASD Clinical
and Research Services

Policy Wise 2017 DATA
Clinical Implications and Future
Research



What the data tells me based on 20 years of FASD practice!

- Data supports FASD “intuitive knowledge” from caregivers, clinicians and individuals living with FASD
- Complexity
- Involves all systems of care
- Lifelong disability
- Need for collaboration, communication and coordination of care: 3 C’s
- Need for shared case conferencing and decision making with identification of MRP
- Need for transition planning to adult services



Prevalence Data in Sample: 05/06-10/11

- <0.2% diagnosed with FASD, n = 3,025 in study period
- Limitations:
 - Sample capture (ORS data not included)
 - Based on 2005 Canadian Guidelines
 - Before Physician diagnostic code training on 760.71
 - Diagnostic capacity not meeting needs but with the CMC Network model: multiple DX clinics close to home community to connect and educate local resources: best in Canada!
 - Who accesses DX: stigma, awareness, kids in care, SDOH
 - Who does **NOT** come for DX: not asking the PAE history, ADHD clinic door, bias
 - Age limitations in DX: preschoolers, adults



High Service Use Across all Systems

- Special education needs 51-57% vs 8% at any point across the 6 years
- Lower educational achievement 38-41% vs 83-85%
- Receiving 2 or more government services 51-56% vs 4-5%
- Child intervention services 32-37% vs 1-2%
- FSCD-FASD supports 24-26% vs 1% (lower as kids in care do not access FSCD but are supported by children's intervention services)
- Enrolment in post secondary 3-5% vs 21-24%
- Criminal offences 13-17% vs 7%
- High health care costs 64% vs 17%
- High mental health needs 74% vs 14%
- Access to adult support services AISH 24-38% PDD 17-30% vs 0.5-1%



What does this service use reflect?

- FASD results from brain damage from prenatal alcohol exposure that affects core areas of function: learning, behavioral and emotional regulation, judgment and other executive function, functional communication that leads to maladaptation; care giver or school is often the first red flag
- Often compounded by toxic stress in the pregnancy and early years (Prevention opportunity!)
- Services in brain damage model are needed in every sector including supports for caregivers and across the lifespan
- Ongoing needs: identify, implement and evaluate evidence based best practices, improve access to services with service navigation, including transition to “what “ in adult services



Child Intervention Services

- Over representation of individuals with FASD (32-37%) accessing this service (vs 1-2%) why? Link in SDOH
- Child maltreatment/inadequate care and use of alcohol in pregnancy are linked to SDOH “why women drink?” poverty and multigenerational trauma (Prevention opportunities!)
- Multiple moves in FASD (6-7% more than 2 moves) may be linked to foster care moves which can impact developing a healthy attachment relationships (Prevention opportunity!)
- More FASD in lower income (39-41%) may be related to biological family of origin but also the foster system or burden of care on the family: need to explore this further

It is not Healthy to have FASD!

- FASD is a whole body disorder ARBD (Alcohol Related Birth Defects) vision, cardiac defects, hearing, immune system, sleep patterns, multiple neuroreceptor systems
- Early trauma compounds health through ACE study data
- Asthma (16.5% vs 8.3%) poverty, smoking exposure, housing issues SDOH, impact of PAE on immune system
- Increase in diabetes may reflect over representation of FN in sample with increase genetic risk or medication effect of atypical psychotic drug use (CAMSE).
- Need long term data on life expectancy in FASD



Mental Health and FASD

- 45-50% of individuals with FASD accessed a mental health service (excluding psychologists/social workers)
- 2015 Canadian Guidelines for FASD DX look at domain 10 of affect regulation to be considered in Dx criteria
- Ongoing dilemma is whether MH is related to PAE or adverse life experiences or both?
- Service delivery needs to be trauma informed and are we there yet in mental health service delivery?
- Questions and gaps: access to mental health services at key points across the life span especially in early years and in transition to adult services



Next Steps

- **Alberta leads/rocks!** across the country in all areas in FASD but that is not enough; KT opportunities “spread the word”
- Data collection with the Canada FASD Research Network Database: DX profile and recommendations
- Compare data from other disability populations PRRS: ASD & CP CAPHC
- Data informs where we have come from but also where we need to go: new research and evaluation questions, identifying best practices
- Longitudinal data
- Qualitative data: the lived life experiences



Next speaker

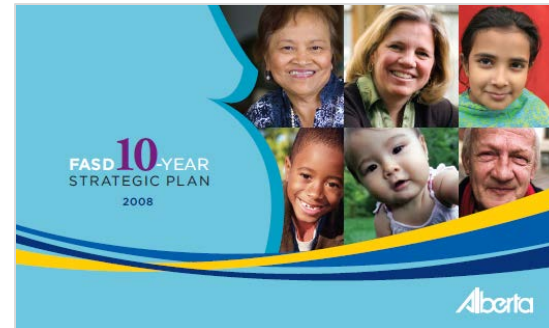


- Janice Penner

A Cross-Ministry Perspective

Data: *a tool for informed-thinking*






- Policy and Practice
- Responsibility
- Program Implications



A Cross-Ministry Perspective

Policy and Practice

- Data as a tool
- Data raises questions
- Data tells us:
 - We are on the right track
 - We may need to shift focus
 - We may need to change practice



6. Research and Evaluation

Definitions:
Research refers to basic scientific and applied research leading to increased understanding of FASD, its epidemiology (i.e., incidence and prevalence), leading practices in the prevention and treatment of FASD, and development of standards to guide the delivery of FASD clinical services and/or FASD programming.

Target Groups:

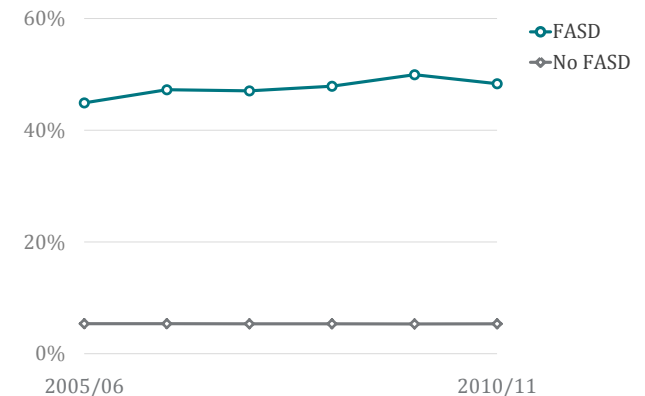
- Government of Alberta ministries
- FASD service providers
- Post-secondary institutions
- Clinicians

Outcome 6:
Basic and applied research findings, including those from monitoring and evaluation systems, are used to inform FASD strategic planning, FASD prevention activities and FASD related programming.

Gaps:
Available data suggests that research infrastructure is being developed, particularly at the provincial level. There is recognition that individual agencies at the community level are actively conducting their own research as part of program planning, and therefore does not appear in the current analysis. The primary gap exists in the lack of a mechanism to support coordination of research at the provincial level. Historically, there was no mechanism to allow the government to participate in or influence regional and community-level research agendas across the province.

Alberta
Government of Alberta - FASD: It's Not Enough This

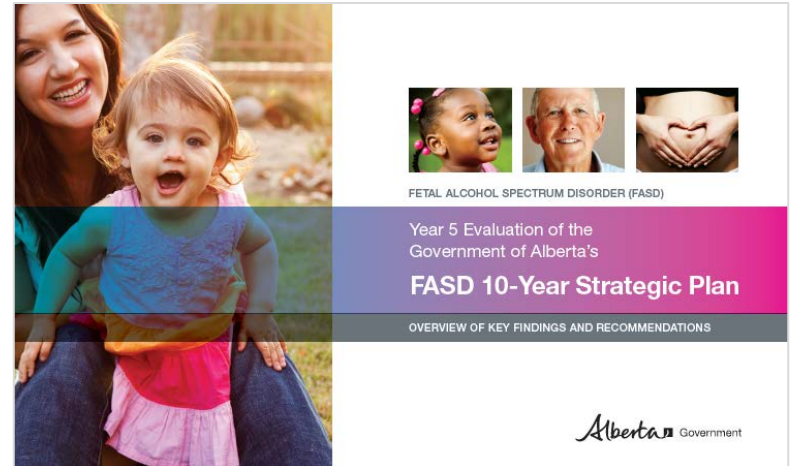
Percentage of Albertans aged 0 to 25 with mental health service use over time



A Cross-Ministry Perspective

Responsibilities

- Accountability
- Measures Progress
- Analysis
- Interpretation
- Question
- Outcomes
- Feedback Loop
- Respect



“A higher proportion of young Albertans living in the Northwest and North Central regions had FASD than in other Alberta regions.”

A Cross-Ministry Perspective

Program Implications

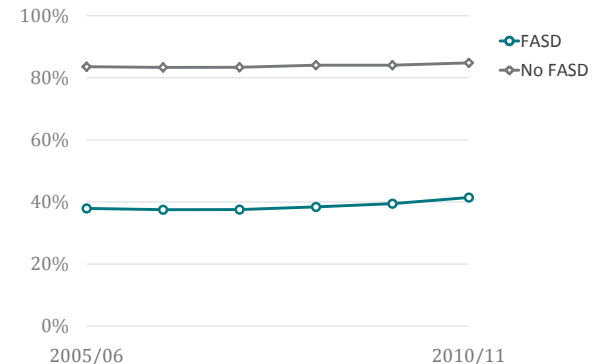
- Achievements
 - PCAP
 - Prevention Conversation
- Gaps
 - Early identification of FASD
 - Educational achievement
- Priorities
 - Knowledge and capacity development

Albertans will be better served because government will understand at-risk populations and areas of need in the province



<https://preventionconversation.org/>

Percentage of Albertans in grades 3 to 12 meeting or exceeding educational expectations over time





Policy Wise

for Children & Families

mobilizing evidence to inform policy

cwerk@policywise.com

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