Using data to change systems:
Moving Beyond Compliance

Early Intervention ILP Infant Learning Program

Expectations

- How Alaska learned to use data
- ACES
- Using data to inform policy
- Program strategies using Child Outcome data

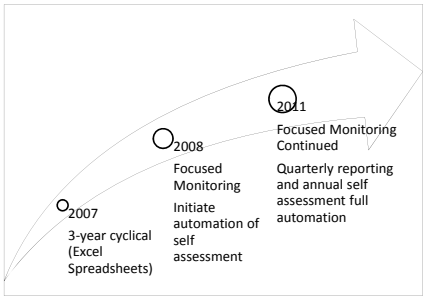
2

Early intervention in Alaska

- DHSS
- 16 grantees
- Urban, rural and remote
- Culture

3

History of Alaska Monitoring



Compliance Monitoring

Indicators Automated – annual comparison

- 1 Timely Services
- 2 Natural Environment
- 3 Child Outcomes
- 7 45-Day Timeline
- 8 Timely Transition
- 9 Correction of noncompliance

Compliance Monitoring

Indicators not automated

- 4 Family Outcomes Statewide Survey
- 5-6 Child Find 618 data
- 10-13 Due Process manual tracking
- 14 Timely, Accurate and Reliable Data manual tracking

Quality Monitoring

- Monitoring Committee identified:
  - Related Requirements (IDEA)
  - Best Practice (Alaska Quality)

28 Question Annual Self Assessment

Related Requirements

- Written Prior Notice (303.403(b))
- Parental Consent (303.403(b))
- Family Primary Language (303.403(c)),(303.323(a)),(303.342(d)(1)(ii))
- Decline IFSP Service Documentation (303.40
- Service Provision Consistent with Consent (3
- Multidisciplinary Service Providers (303.17)
- Family Assessment (303.322(d))
- Eval Includes Other Sources (303.17, 303.322(c)(3)(i))
- Comprehensive Eval (303.322(c)(3))
- Documentation of Untimely Transition Meeting (303.148(b)(2)(i))

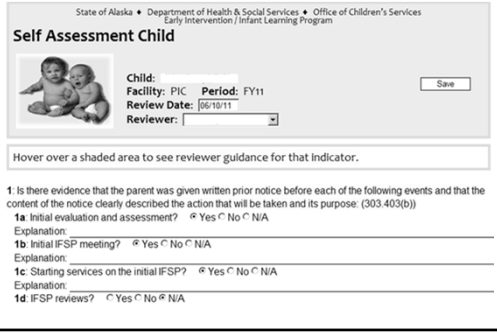
Best Practice – Alaska Quality

- COSF Consistent with Eval
- Functional Eval
- Parent Observation
- Functional Service Strategies
- COSF to inform systems/services

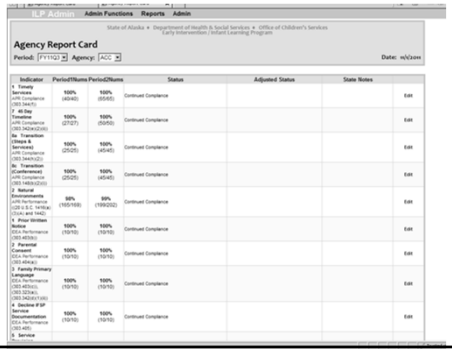
Quality Assurance & Monitoring

- State level TA Quarterly or as needed
  - Local staff training
- Annual verification visits
  - 3- year cyclical on-site file review or as needed
- Annual self assessment
  - Mid-year child level self assessment for correction of noncompliance
- On-site Monitoring
  - Local root cause analysis for longstanding noncompliance

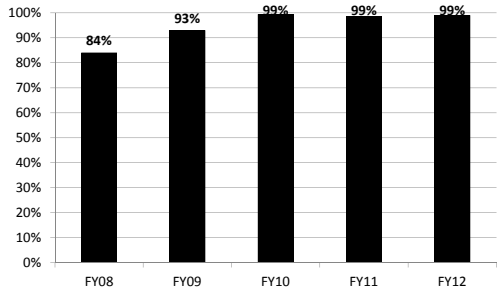
Self Assessment



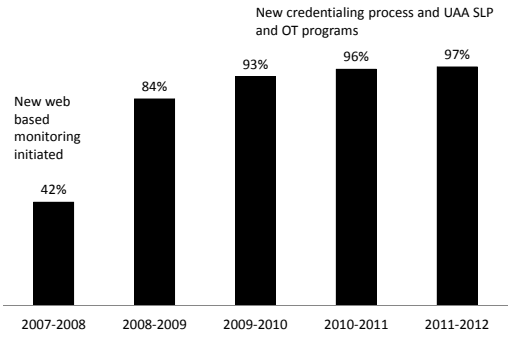
Annual Report Card



Percent of Enrollments within 45 Days of Referral



Timely IFSP Services Delivery



Alaska EI/ILP Database

Questions

Personal reflection

- Early Childhood Mental Health
  - TACSEI/Alaska Pyramid Partnership
- CAPTA
- Professional Development
- Program improvement

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The Adverse Childhood Experiences (ACE) Study

Examines the health and social effects of ACEs throughout the lifespan among 17,421 members of the Kaiser Health Plan in San Diego County

What do we mean by Adverse Childhood Experiences?

- **Childhood abuse and neglect**
  Growing up in the home with
  - **domestic violence,**
  - **substance abuse**
  - **mental illness,**
  - **parental discord**
  - **Crime**

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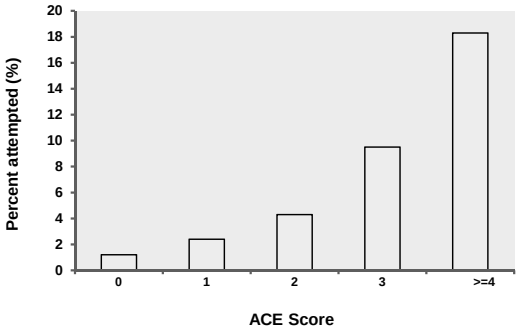
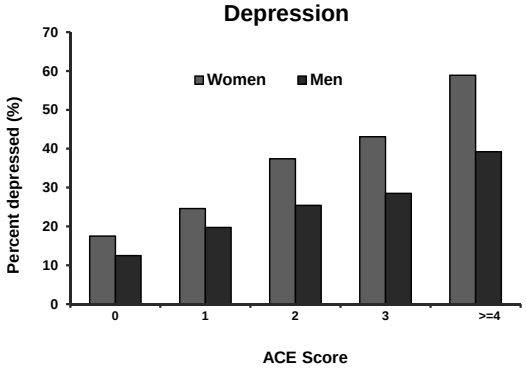
The ACE Score and the Prevalence of Attempted Suicide



18

The ACE Score and a Lifetime History of Depression



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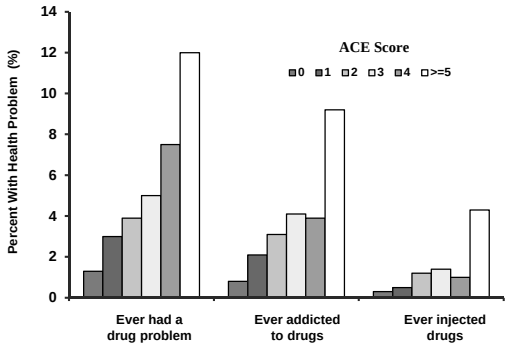
ACE Score and Drug Abuse



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ACES Lead to Trauma and Potential Long-Term Outcomes

Neglect in infancy - Sexual abuse at ages 9 and 10

-Adaptation:

- Language delay
- Diminished math capacity
- Diminished integration & coordination
- Difficulty with social cues

Witnessing DV -Sexual abuse

Adaptation:

- Poor executive function
- Impulsiveness
- Diminished abstract reasoning
- No hope for the future
- Limiting field of vision

All forms of maltreatment in the first 2-3 years of life - Sexual abuse at ages 3-5

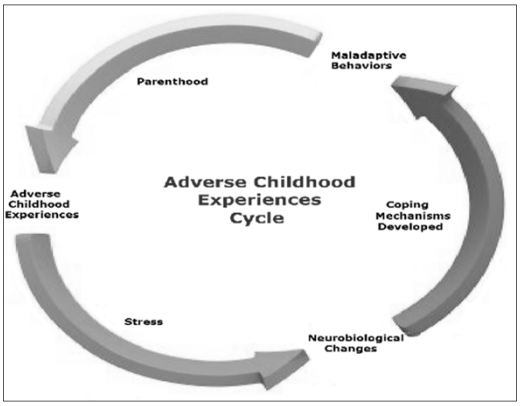
Adaptation:

- Emotionally reactive— brain's braking mechanism fails
- Poor regulation of behavior
- Difficulty with verbal & spatial memory

TRAUMA IS HARD-WIRED INTO BIOLOGY

All forms of maltreatment in the first 2-3 years of life - Sexual abuse at ages 3-5 - Neglect in infancy - Sexual abuse at ages 9 and 10 - Witnessing DV -Sexual abuse

21



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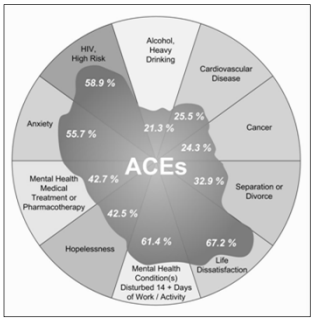

POPULATION ATTRIBUTABLE RISK

ACE reduction reliably predicts simultaneous decrease in all of these conditions.

Bridging The Chasm

Child health as it stands today

Breakthroughs in molecular genetics and biology:
Mental illness
Substance abuse
Violence

Improved recognition and treatment of:
Mental illness
Substance abuse
Domestic violence
Child abuse

Mass education about child development & parenting:
Media
Schools

Documenting the societal burden of child health as it stands today

New directions in prevention and treatment

Child health as it could be

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Bridging The Chasm

Child health as it stands today

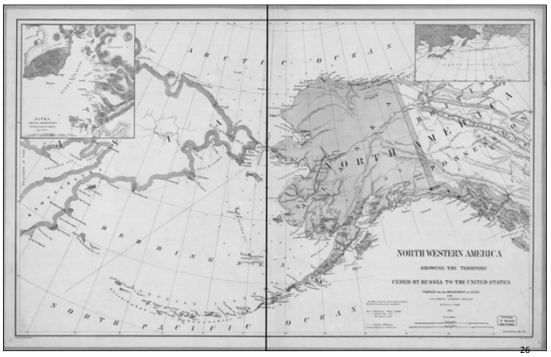
Involving those who don't yet realize that they are working on issues that represent the "downstream" wreckage of child abuse and neglect--and other adverse childhood experiences--in the effort to bridge the chasm.

Routine screening for trauma is needed

Child health as it could be

25

What about Alaska?



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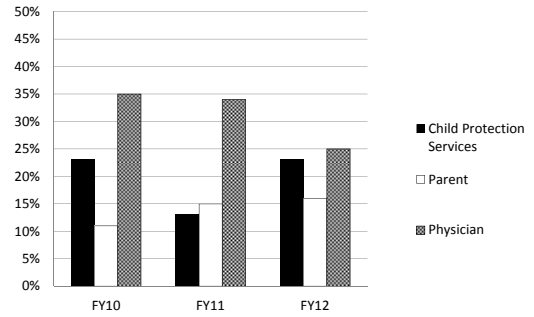
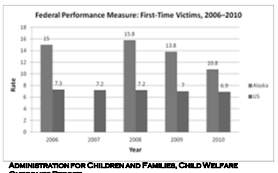
Top Referral Sources Part C

July 1, 2009 – June 30, 2012



Emotional Abuse, Physical Abuse, Sexual Abuse, Emotional Neglect & Physical Neglect

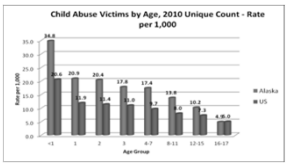
First time victims per 100,000 children



Administration for Children and Families, Child Welfare Outcomes Report,

Alaska ranked second worst of all states in child victims with a rate of 21.6 per 1,000 children in 2009.

Administration for Children and Families, Child Welfare Outcomes Report, http://cwoutcomes.acf.hhs.gov/data/overview/victim_rate



Administration for Children and Families, Child Welfare Outcomes Report,

In 2008 Alaska Ranked Third Worst in rate of substantiated child abuse cases per child population.

Administration for Children and Families, Child Welfare Outcomes Report, http://www.acf.hhs.gov/programs/cb/pubs/cmos/table3_1.htm

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Adverse Childhood Experiences in Alaska

Some Things We Know…… and Some We Don't

- Physical abuse/neglect
- Emotional abuse/neglect
- Sexual abuse
- An alcohol and/or drug abuser in the household
- Incarcerated household member
- Household Mental Illness
- Mother is treated violently
- Parental Separation/Divorce

http://www.cdc.gov/ace/prevalence.htm

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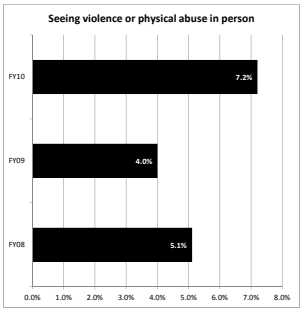
Children 3 and Under Witnessing Violence



Note: Survey of Mothers with children under three years old.
Source: CUBS, Alaska Division of Public Health.

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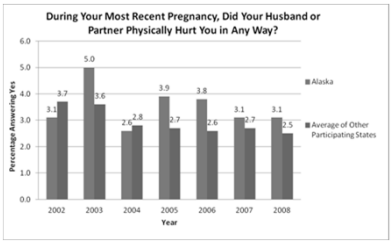
Pregnancy



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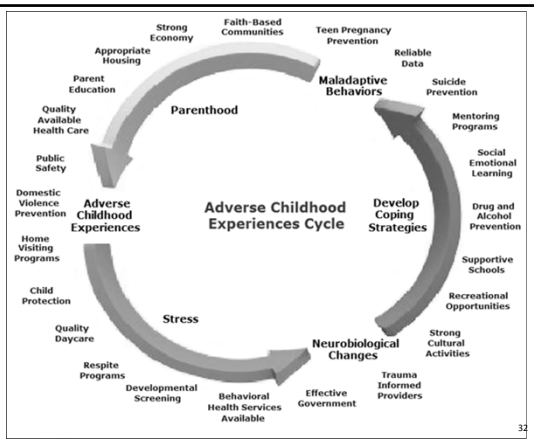

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Thoughts?

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Alaska Early Childhood Mental Health-

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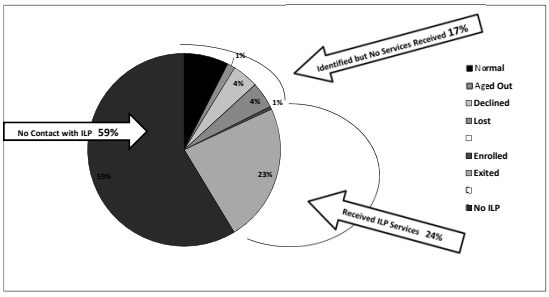
Changes in Mean Age of Children 0-7 Receiving Medicaid Behavioral Health Services Between FY08 & FY10 by Diagnostic Category

Diagnoses	FY08	FY10	% Change
Post Traumatic Stress Disorder	5.4	5.2	-3.9%
Deprivation Maltreatment Disorder	5.0	4.0	-20.0%
Anxiety Disorder of Infancy and Early Childhood	5.1	5.3	3.3%
Depression of Infancy and Early Childhood	5.5	5.3	-3.3%
Adjustment Disorder	5.2	5.1	-1.0%
Regulation Disorders of Sensory Processing	5.7	5.7	-1.0%
Sleep Behavior Disorders	2.8	2.6	-8.9%
Feeding Behavior Disorders	1.9	1.7	-12.6%
Disorders of Relating and Communicating	4.3	4.5	5.8%
Conduct Disorders	4.2	4.6	10.8%
Bipolar or Cyclothymic	5.3	5.9	11.2%
Substance Abuse	3.5	1.1	-67.9%
Enuresis/Encopresis	4.9	5.3	8.6%

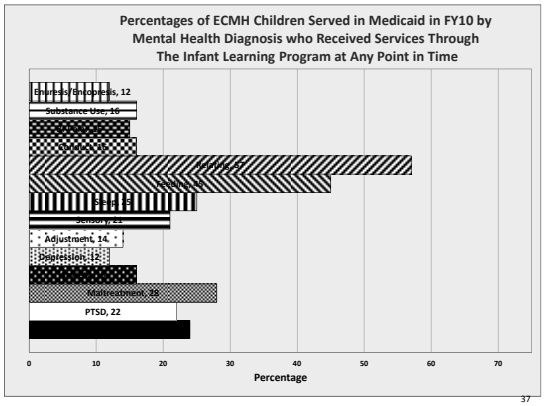
35

Children 0 – 7 who had a BH Billing (2010 data) and Their ILP Participation



Normal – Children who were screened or evaluated as in the developmental range
Aged Out – Children who were too old to receive services
Declined – Declined assessment or services
Lost – Referred but lost before contact could be made
Enrolled – Children currently enrolled
Exited – Children who received services in the program
No ILP – Refers to children with no contact with ILP

36



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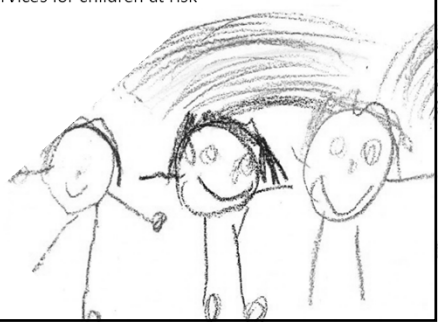
Extended Eligibility Pilot 2009-2011

- providing services for children at risk



Enhanced practices

- ASQ-SE
- reflective practice
- MH consultation

Greenspan Social-Emotional Growth Chart[1,3]

- 76% experienced measurable increases in social-emotional skills
- Overall difference between entry and exit/annual standard scores was statistically significant (p = .002)

Subpopulations in 20-month Pilot(1)

- 25% to 49% developmental delay (85%)
- CPS-involved (child welfare system) (22%)
  - Foster parent referred
  - Parent referred after contact with CPS
  - Substantiated reports of harm (CAPTA)
  - Unsubstantiated reports of harm
  - Investigations pending
- CAPTA (substantiated reports of harm) (12%)
- Other risk factors (not included in any of the above categories) (10%)

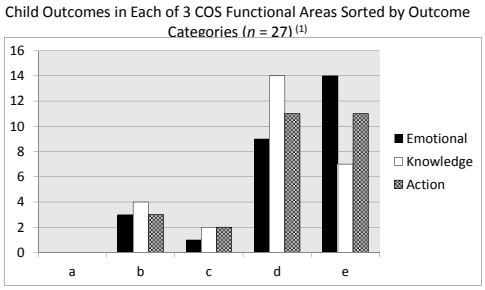
Demographics(1)

- 73 children were initially enrolled in pilot services
- Most typical child was…
  - Between one and two years old (42%)
  - Male (60%)
  - White (60%)
  - Had a 25% to 49% developmental delay (85%)
  - Was living with family (96%)
- Alaska Native or American Indian was indicated for 27% of children
- At the end of the pilot, 31 (42%) were still enrolled and 42 (58%) had exited
- About 45% of exited children had received a course of intervention

Child Outcome Summary (COS) (1,2)

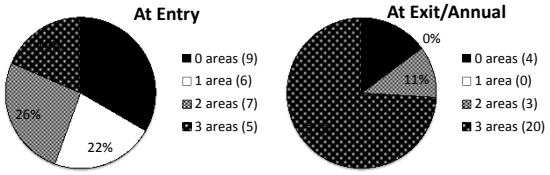
- 27 children had both entry and exit or annual ratings in three functional areas
  - Emotional: Children have positive social-emotional skills
  - Knowledge: Children acquire and use knowledge and skills
  - Action: Children use appropriate behaviors to meet needs
- Outcome categories (compared with same-age peers)
  a. Did not improve functioning
  b. Improved, but not sufficient to be nearer peers
  c. Improved to a level nearer peers, but not the same*
  d. Improved to a level comparable with peers*
  e. Maintained a level comparable with peers

*Highly unlikely to occur without intervention



70% showed improvements of a magnitude highly unlikely to occur without intervention

Age-appropriate functioning in number of COS areas (*n* = 27) (1)



81% entered with some low functioning, 74% exited with age-appropriate functioning in all 3 areas

Child Outcome Summary 1 FY12

Children who entered the program below age expectations - % who substantially increased their rate of growth by the time they exited the program.	**Emotional Development**	**Gaining New Skills and Knowledge**	**Taking Action to Get Needs Met**
Target	68%	78%	74%
Actual	**69%**	**70%**	**73%**

Child Outcome Summary 2 FY12

Percent of children functioning within age expectations by the time they exit the program.	**Emotional Development**	**Gaining New Skills and Knowledge**	**Taking Action to Get Needs Met**
Target	58%	60%	55%
Actual	**55%**	**45%**	**48%**

Enhanced data

- Using tables to investigate outcome areas for sub-populations
  - Medicaid Eligible
  - Referred through Child Welfare
  - Referred through physicians office

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- http://acestudy.org/