

Linking data to build an evidence base: The WA Developmental Pathways Project

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Australia vs California

Population of
California- 38 million

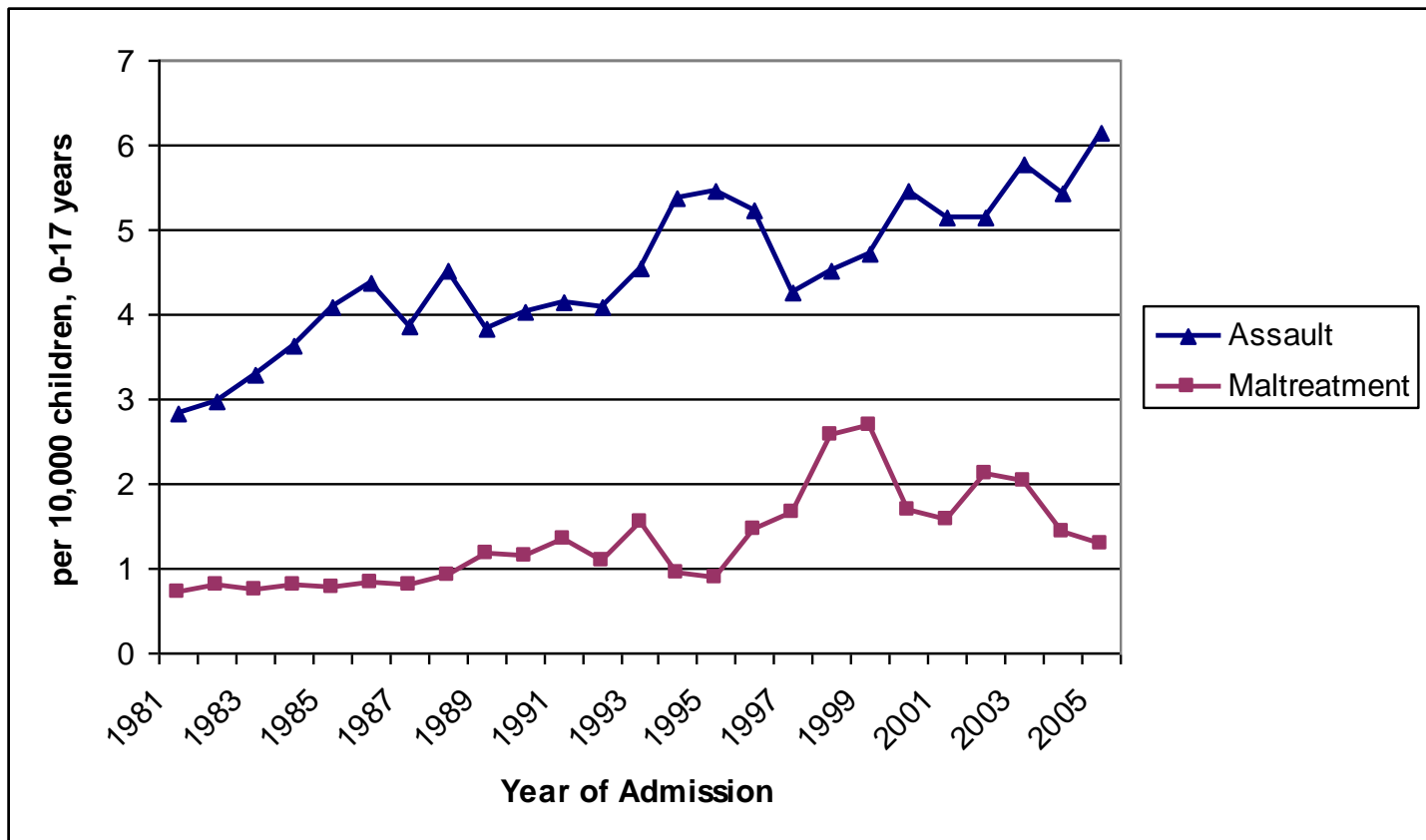
Population of Western
Australia- 2.5 million



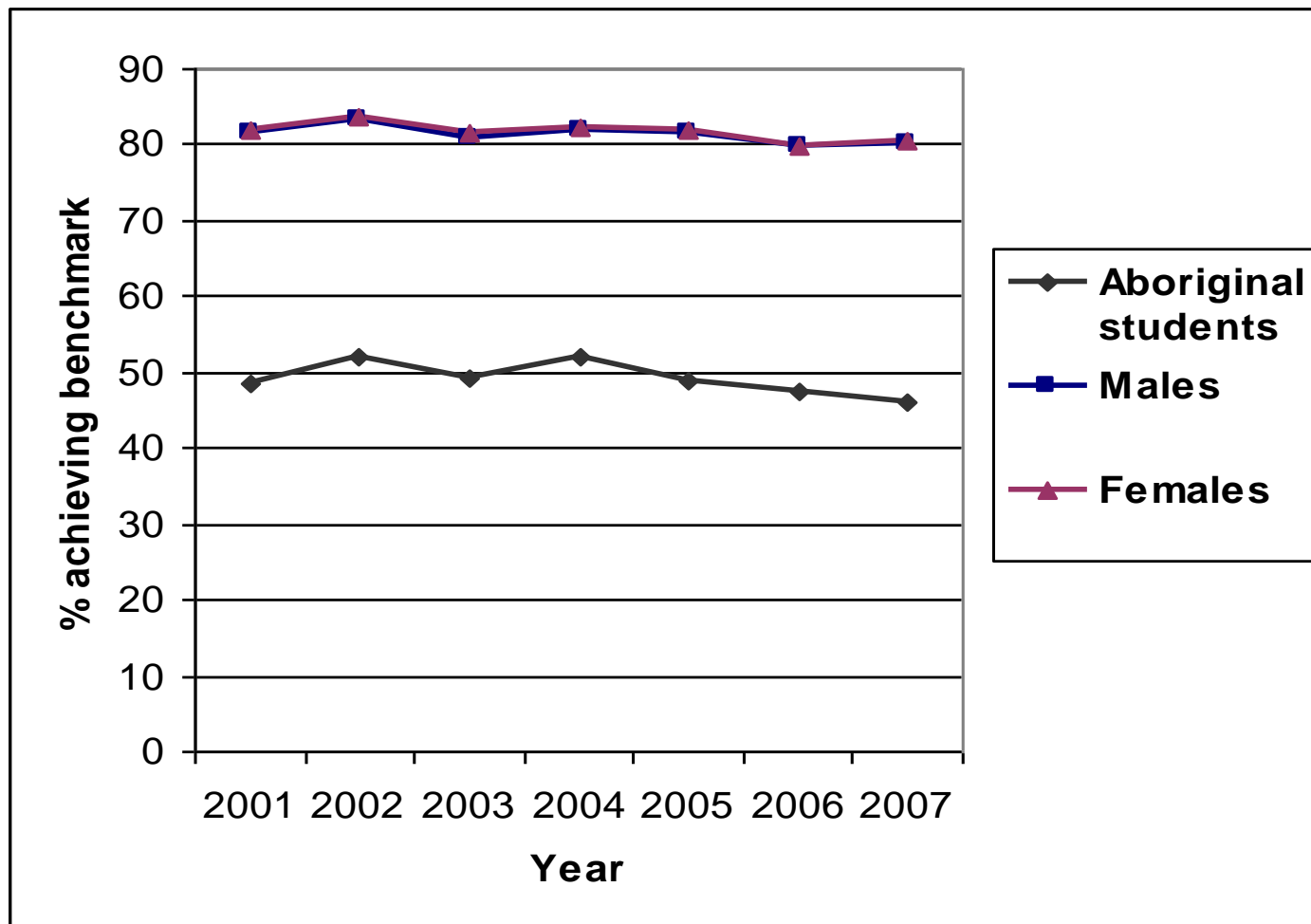
Why set up a data linkage system?

The Current State of Western Australian Children

Child Maltreatment and Assault Admissions



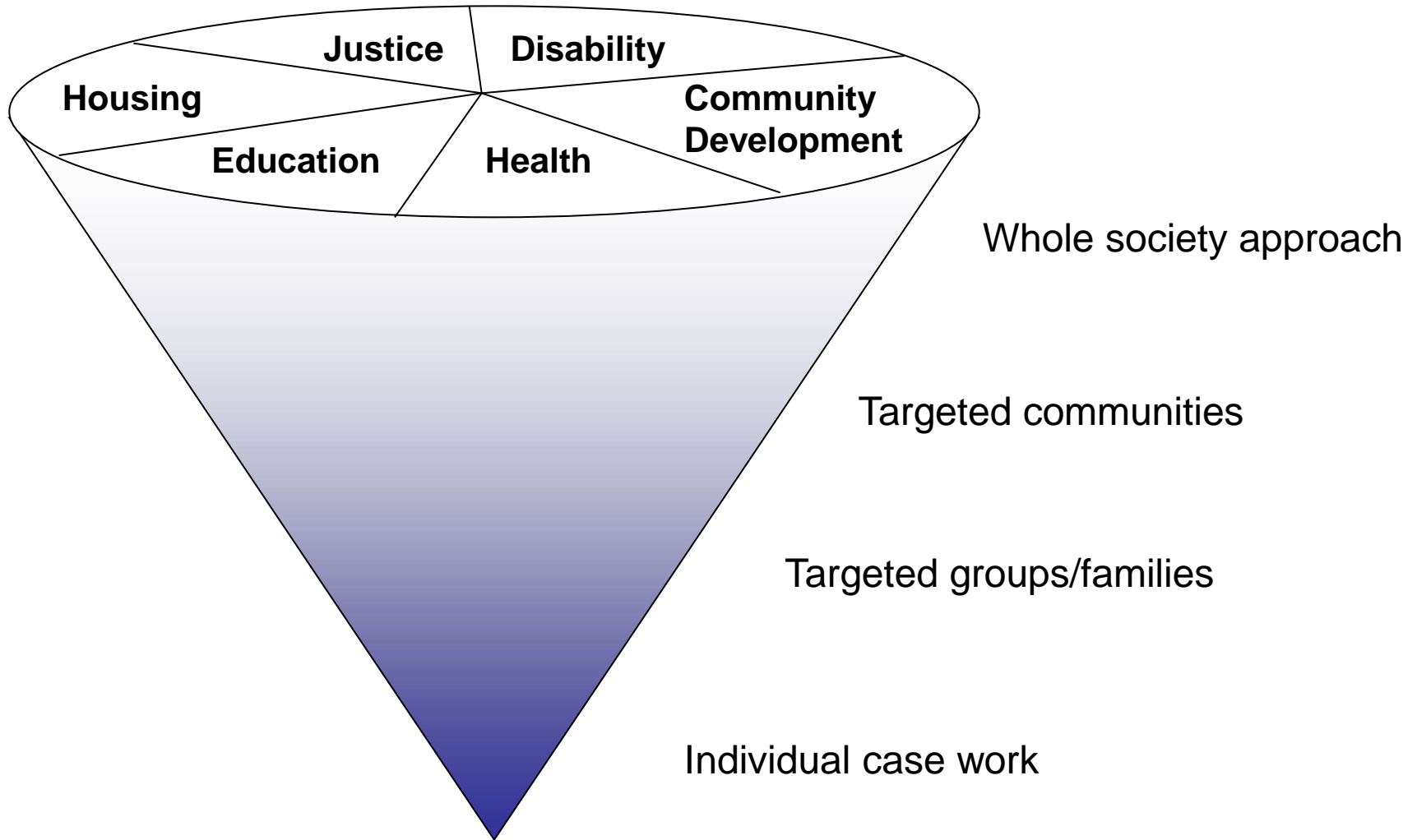
Educational outcomes: Numeracy



“Joined-up” thinking

- Complex problems have multiple causes and demand cross-agency responses
- Complex problems appear to be increasing especially for children and adolescents
- Complex problems need to be prevented. Such prevention policies need cross-agency, joined-up thinking
- Current responses focus too late, do not appreciate multiplicity of interacting causal pathways

Prevention/Intervention Model



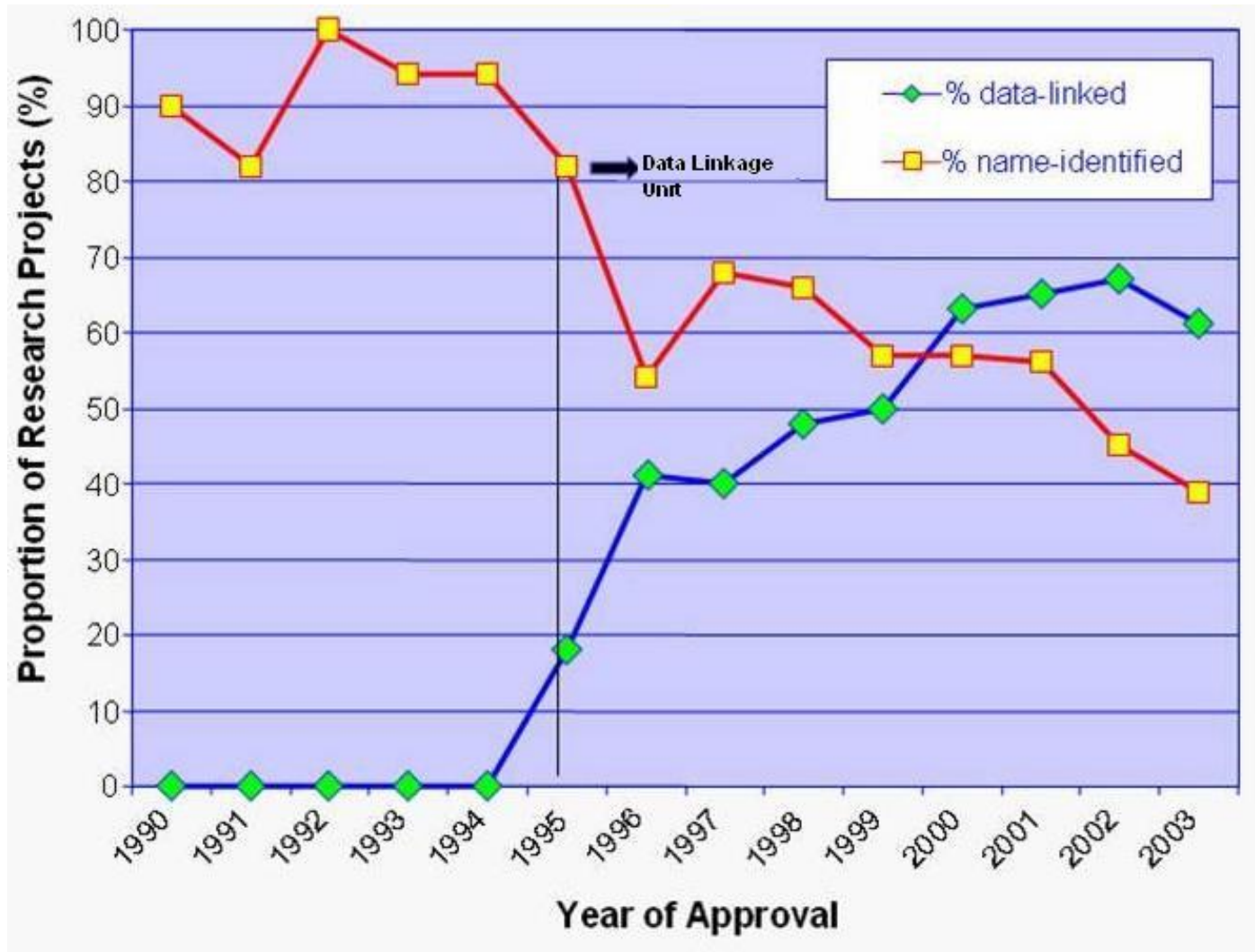
WA Developmental Pathways Project

Western Australian Data Linkage

- Since 1970's
- Data Linkage Branch
- Well-established relationships
- Linked using demographic data
- De-identified data given to researchers



Minimising risk to privacy



Source: Trutwein, B. et al, (2005)

DPP Partners

WA Department	Partner Investigators – Directors General
Treasury	Tim Marney
Health	Bryant Stokes
Education	Sharyn O'Neill
Child Protection and Family Support	Terry Murphy
Attorney General	Cheryl Gwilliam
Corrective Services	Heather Harker
Police	Karl O'Callaghan
Housing	Grahame Searle
Indigenous Affairs	Cliff Weeks
Local Government and Communities	Jennifer Mathews
Disability Services	Ron Chalmers
Mental Health Commission	Eddie Bartnik
School Curriculum and Standards Authority	Steve Donatti



HEALTH DATA

Midwives Notifications (1980-*ongoing*)
Birth Registrations (1980-*ongoing*)
Hospital Morbidity Database (1970-*ongoing*)
Mental Health Register (1970-*ongoing*)
Death Registrations (1980-*ongoing*)
Drug and Alcohol Office data (2000-2008)

CHILD PROTECTION DATA

Child Concern Reports (1990-*ongoing*)
Concern for child's wellbeing (2006-*ongoing*)
Child Maltreatment Allegations (1990-*ongoing*)
Substantiated Child Maltreatment Allegations (1990-*ongoing*)
Periods of Care (1990-*ongoing*)

CORRECTIVE SERVICES/POLICE DATA

Juvenile Justice Team Referrals (1990-*ongoing*)
Juvenile & Adult Orders (1990-*ongoing*)
Juvenile & Adult Custodial data (1990-*ongoing*)
Police Cautioning (1990-ongoing)
Domestic Violence Call Outs (1990-ongoing)
Incidents (1990-ongoing)
Court Data (1990-ongoing)

DATA LINKAGE BRANCH

Master Linkage
Files

AUSTRALIAN BUREAU OF STATISTICS/ DEEWR DATA

Australian Census Data (1980-*ongoing*)
Australian Early Development Index (2009-*ongoing*)

DEPARTMENT of COMMUNITY DATA

WA Best Start Program (2009-ongoing)

DEPARTMENT OF HOUSING DATA

Public Housing Data (1970-ongoing)

EDUCATION DATA

Literacy & Numeracy Assessment Data (1999-*ongoing*)
Student Attendance (2004-ongoing)
Student Suspensions (2004-ongoing)
WACE- 2010- ongoing

DISABILITY DATA

Intellectual Disability Exploring Answers (1980-*ongoing*)
Cerebral Palsy Register (1980-*ongoing*)
Birth Defects Register (1980-*ongoing*)



HEALTH DATA

- Midwives Notifications (from 1980)
- Birth Registrations (from 1980)
- Hospital Morbidity Database (from 1970)
- Mental Health Register (from 1970)
- Death Registrations (from 1980)
- Drug and Alcohol Office data (2000-2008)



CHILD PROTECTION DATA

- Child Concern Reports (from 1990)
- Concern for child's wellbeing (from 2006)
- Child Maltreatment Allegations (from 1990)
- Substantiated Child Maltreatment Allegations (from 1990)
- Periods of Care (from 1990)



EDUCATION DATA

- Literacy & Numeracy Assessment Data (from 1999)
- Student Attendance (from 2004)
- Student Suspensions (from 2004)
- Certificate of education- (from 2010)
- Australian Early Development Index (from 2009)



CORRECTIONS DATA

- Juvenile Justice Team Referrals (from 1990)
- Juvenile & Adult Orders (from 1990)
- Juvenile & Adult Custodial data (from 1990)
- *Court Data (from 1990)*
- *Police Cautioning (from 1990)*
- *Domestic Violence Call Outs (from 1990)*
- *Incidents (from 1990)*



DISABILITY DATA

- Intellectual Disability (from 1980)
- Cerebral Palsy Register (from 1980)
- Birth Defects Register (from 1980)

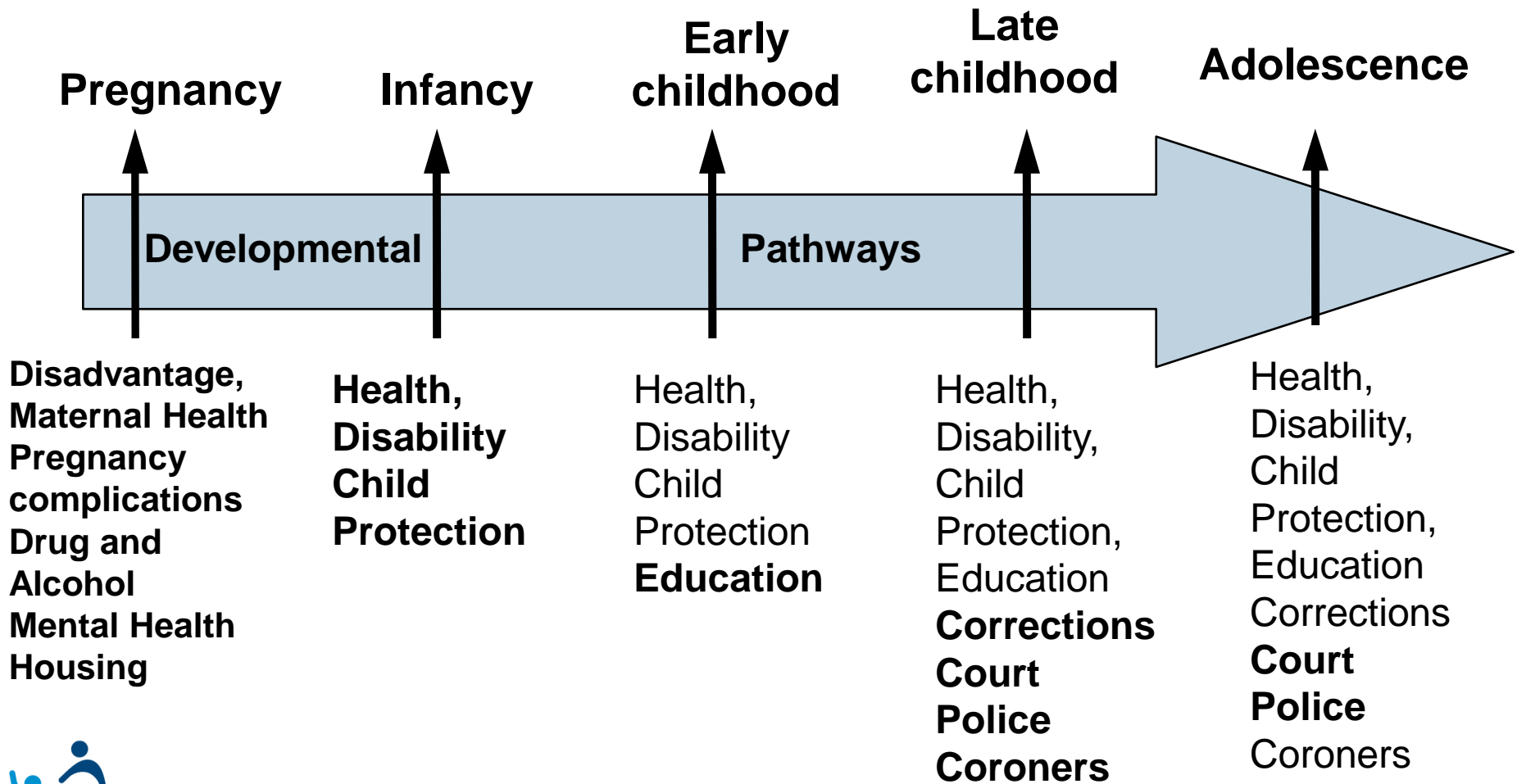


HOUSING DATA

- Public Housing Data (from 1970)
- Waitlist data (from 1970)

New datasets to be sourced

- Child health nurse data
- Best start data
- Data on services
- Benefits
- Pharmaceuticals



Cross agency data linkage- The advantages

- 1) Total population – capture at risk children
- 2) Existing Data
- 3) Cheap
- 4) De-identified
- 5) Statistically Robust (power, unbiased, vulnerable groups)
- 6) Changes over time
- 7) Policy evaluation
- 8) Analyses of very sensitive information



Areas of investigation

- Changing trends across several outcomes for WA children
 - Common child, parental and community risk and protective factors across outcomes?
 - Which modifiable factors can be targeted to improve outcomes?
 - Are outcomes mediated by contact and interventions by government agencies?
- EVALUATION of services

COMMUNICATION

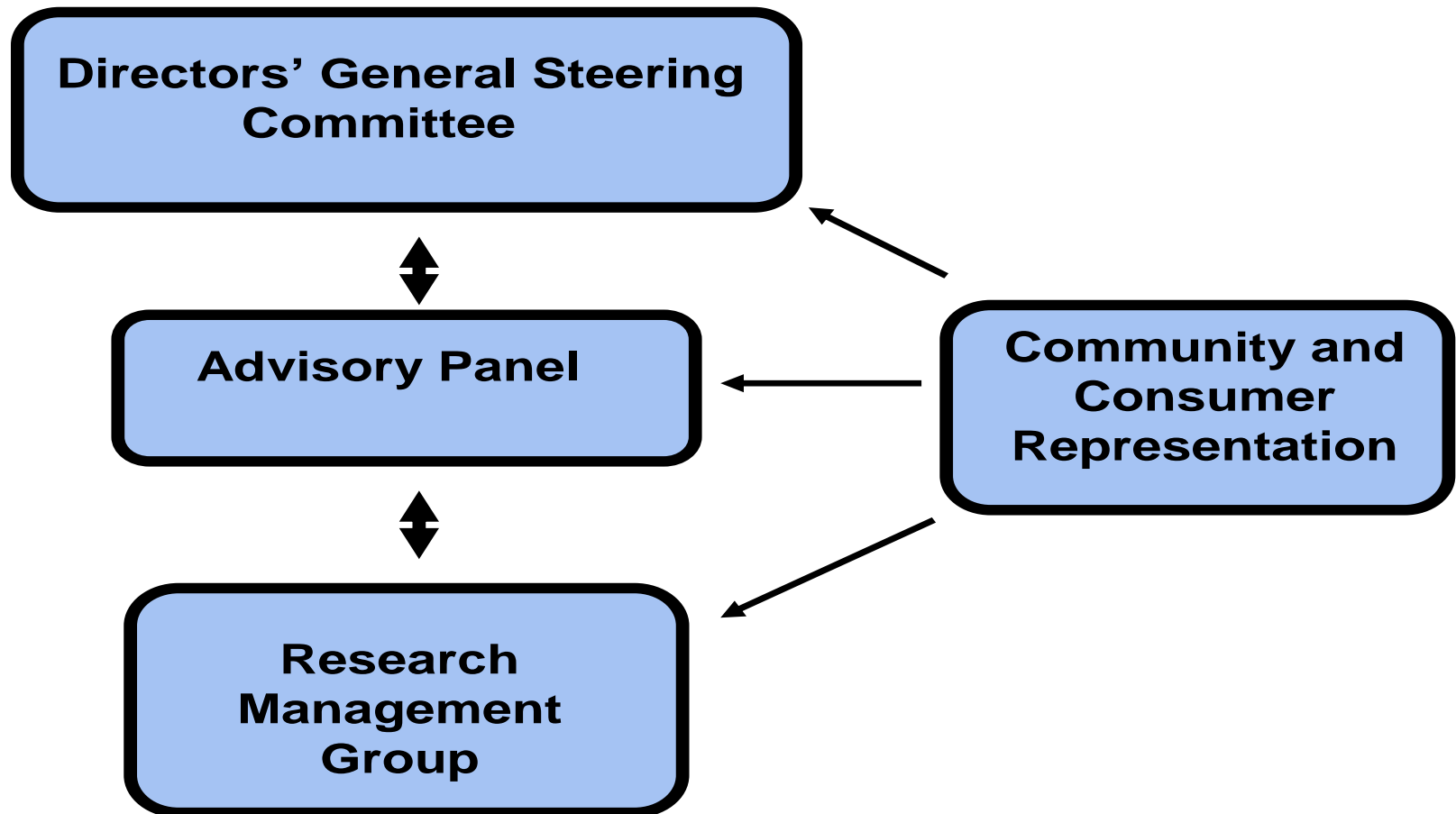
- Memorandum of Understanding for each agency
- Confidentiality agreements
- Ethics approvals
- Review of papers/presentations
- Community consultations

How we use our findings

- Briefing papers for government and community
- Academic papers
- Presentations:
 - Clinicians
 - Government agencies
 - Hospitals
 - Community groups
- Media



DPP Governance Structure



Supported by WA Gov legal and information governance

Examples of some projects

- The relationship between education and mental health outcomes for Western Australian children
- An evaluation of Supported Accommodation Services in Western Australia
- A population-based study of the prevalence and frequency of offending and the influence of individual, family and community factors on delinquency in Western Australian children



- Alcohol and Pregnancy: The impact of low to moderate maternal alcohol consumption on child health and developmental outcomes
- Risk factors and outcomes of children prescribed stimulant medication for ADHD
- Towards prevention – A population health approach to child abuse and neglect: A measurement model and the identification of antecedent causal pathways



Summary

- Linked data can provide information on risk and protective factors, trends, evaluations, monitoring and outcomes.
- This system gets government WORKING TOGETHER- outside of silos
- Geography can be used by Government and community groups to provide appropriate services and support systems for where there are problems.

The Trojan- 5 attributes

- **Faithful**- you need dedicated people who believe in your cause
- **Scholarly**- you need people with foresight and vision, who understand the importance of what you are doing
- **Skillful**- a data linkage program involves many skills, from the engagement of agencies, custodians and communities, the actual linking of data, the analyses of that data, and then to the translation of the findings.

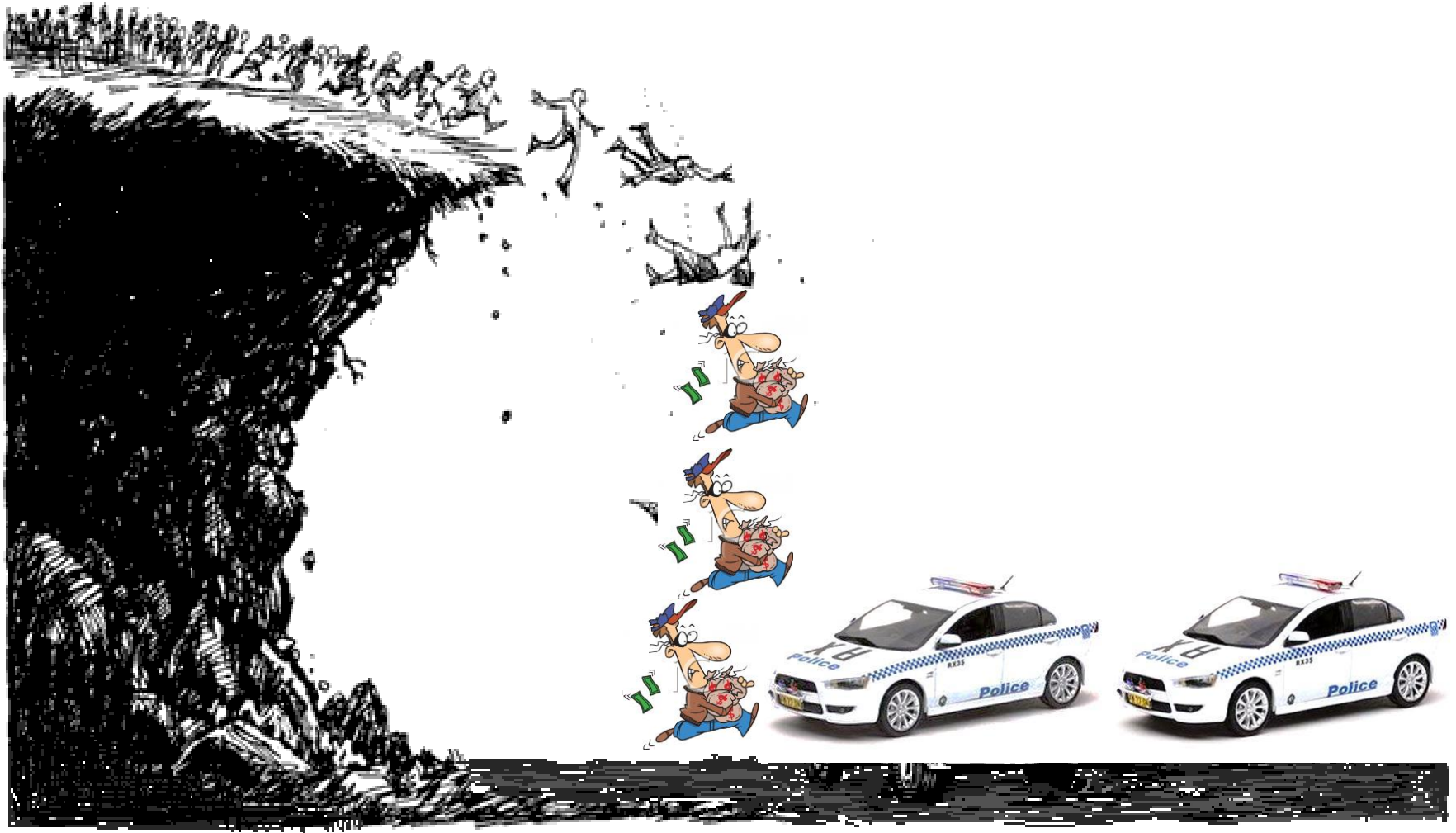


The Trojan- 5 attributes

- **Courageous**- starting up a data linkage program takes courage- on many fronts! People may be suspicious, opposed, reluctant. You will get knock backs all the time, but you have to keep trying- you will eventually succeed.
- **Ambitious**- you need ambition- and a lot of it! There are continuous struggles, developments and REWARDS!



Crisis or Prevention?



Acknowledgements

Chief Investigators and other researchers involved in DPP

- Prof Fiona Stanley - Dr Natasha Nassar -Dr Jianghong Li
- Dr Amanda Langridge - Dr Rebecca Glauert - Dr Melissa O'Donnell
- Prof Helen Leonard - Prof Nick De Klerk
- Prof Steve Zubrick - Prof Cate Taylor

WA Data Linkage Branch

Industry Partners - across WA state agencies

Consumer and community advocates

Western Australian Citizens for the use of their data

Australian Research Council