An innovative linked data platform to improve the wellbeing of children— the South Australian Early Childhood Data Project

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The past decade has seen a substantial increase in the use of administrative data in both academic and policy research. In the 2016–17 financial year, 259 projects across Australia received linked public data from data linkage units—nearly double the number of projects receiving data in 2013–14 (Population Health Research Network 2018). Over the same period, state and territory governments have invested in internal capability to use data to inform policy and service delivery decisions (for example, New South Wales Government 2018; South Australian Government 2019; Victorian Government 2018). In 2018, the Australian Government response to the Productivity Commission Data Availability and Use inquiry (PM&C 2018) resulted in a range of policy and legislative measures to increase use of public data. A common theme of the response is enabling public benefit while preserving privacy and security, and building community trust.

In this context of increasing access to public data in Australia, this article describes the South Australian Early Childhood Data Project (SA ECDP), a leading example of a de-identified, linked state and Commonwealth administrative data platform, underpinned by principles of public good use.

Public data should be used for public good

There is a clear need to demonstrate public good in the use of public data. This builds broad community support—a 'social licence'—for use of linked administrative data by government and researchers. The principle of beneficence for ethical research involving humans demands that risks to privacy posed by data linkage are outweighed by the benefits (NHMRC et al. 2018). What public good looks like across the broader spectrum of data use in Australia varies, as the administrative data linkage, use and sharing environment is changing rapidly. The Data Availability and Use inquiry (Productivity Commission 2017) and the Australian Government response (PM&C 2018) have highlighted how far Australia has moved from a traditional focus on 'one-off' data linkage for research. Administrative data are now recognised as an important renewable national resource with potential to create added value for government, non-government and community benefit. Balancing benefit, trust, security and privacy in the use of linked administrative data are key to achieving public good.

Achieving public good through use of public data was the founding philosophical principle of the SA ECDP. At inception, this was modelled on more traditional methods of research translation, operationalised through vehicles such as National Health and Medical Research Council (NHMRC) Partnership Grants. This meant proposing discrete research questions with measurable academic outputs, such as peer-reviewed publications and conference presentations. Since that time, the use of the SA ECDP in collaboration with government partners has grown exponentially. This has led to a change in the way of working, understanding that publishing academic papers in high-quality journals will not by itself improve service delivery. The SA ECDP now operates with 2 additional principles—those of rapid response and returning data to source. Rapid response means attempting to provide answers in the short time frames often demanded by policymakers and those who deliver frontline services. Returning data to source means giving priority to communicating research findings back to frontline workers who collect and input the data—this is essential to any data collection quality-improvement process—and increasingly to community groups where possible.

The SA ECDP is a platform directly increasing government use of the best evidence available to inform real, sustainable service change that will contribute to improving outcomes for all children (Box 8.1).

What have we learned from the SA ECDP?

This section showcases snapshots from the SA ECDP that form part of briefs and reports delivered to the South Australian Government. Three case studies are presented: a public health approach to child maltreatment; describing priority populations with high prevention potential; and redesigning a model of care. They represent just a small fraction of outputs generated from the SA ECDP to various parts of government. The majority of the work using the SA ECDP is currently confidential within government. However, many of these reports are likely to be published once they have been considered and approved by the relevant agencies.

The case studies that follow are based on a 'whole-of-population' view that includes the experiences of Aboriginal and Torres Strait Islander communities, but the data are not presented specifically for Aboriginal and Torres Strait Islander people. While the SA ECDP is being used to understand Aboriginal and Torres Strait Islander experiences, the use of those data is governed by Aboriginal and Torres Strait Islander governance groups and cannot be used without their express permission. Aboriginal and Torres Strait Islander–specific data are only discussed in the following case studies where they have previously been released subject to these governance arrangements.

Box 8.1: What is the South Australian Early Childhood Data Project?

The SA ECDP holds linked de-identified administrative data for about 450,000 South Australian children born from 1991 onwards, and their parents and carers. It is an ongoing sustainable platform that receives data updates on a regular basis. Since 2009, nationally competitive research grants and government funds have been used to build the SA ECDP into one of the most comprehensive linked data resources in Australia, able to track children's health and welfare from before birth into early adulthood. The recent addition of family files allows us to examine intergenerational processes and locate twins and siblings within families.

The SA ECDP has several state and Commonwealth data custodians contributing information spanning health, education, welfare and social services, including child protection, and we continue to add to this with data sources such as drug and alcohol services, the Medicare Benefits Schedule and the Pharmaceutical Benefits Scheme. It is also the first research platform to link Commonwealth Centrelink data with state data from South Australia. In addition to routine administrative data, we link data from special collections, such as through hospitals that contribute to the South Australian Trauma Registry, and for specific purposes, such as our work collaborating with the South Australian Child Death and Serious Injury Review Committee. We also link researcher-driven cohort studies and randomised controlled trials into the SA ECDP to enhance bespoke data collections with administrative data and to facilitate future research by enabling long-term follow-up for some outcomes. The data linkage and de-identification process is conducted by SA-NT DataLink and the AIHW for some Commonwealth data.

Our goal is to improve service delivery across health, education and human services to support healthy child development for all children, and for disadvantaged children in particular. The 'joining up' of these data across government agencies has offered new opportunities for examining a broad range of child health and development outcomes. Using the SA ECDP to work towards this goal has only been possible with the support of government partners who have shared our vision for providing better evidence than has previously been available to inform policy, program and practice decisions.

The SA ECDP has been a platform for a number of research and academic partnerships. This has included work with South Australian Government organisations and services—Department of the Premier and Cabinet, Department for Health and Wellbeing, Department of Treasury and Finance, Department for Education, Department for Child Protection, Department of Human Services,

Box 8.1 (continued): What is the South Australian Early Childhood Data Project?

the Child and Family Health Service, the Women's and Children's Health Network, and the Council for the Care of Children—as well as the Wardliparingga Aboriginal Research Unit and the Aboriginal Health Council of South Australia. Most recently, we have started to work with a range of community-based organisations to help them understand factors relevant to local community profiles of child wellbeing and development. The SA ECDP has proven to be a public good research resource with trans-disciplinary and inter-sectoral research partners in academia, government, non-government and community sectors.

Figure 8.1: Data sources held in the South Australian Early Childhood Data Project (SA ECDP)
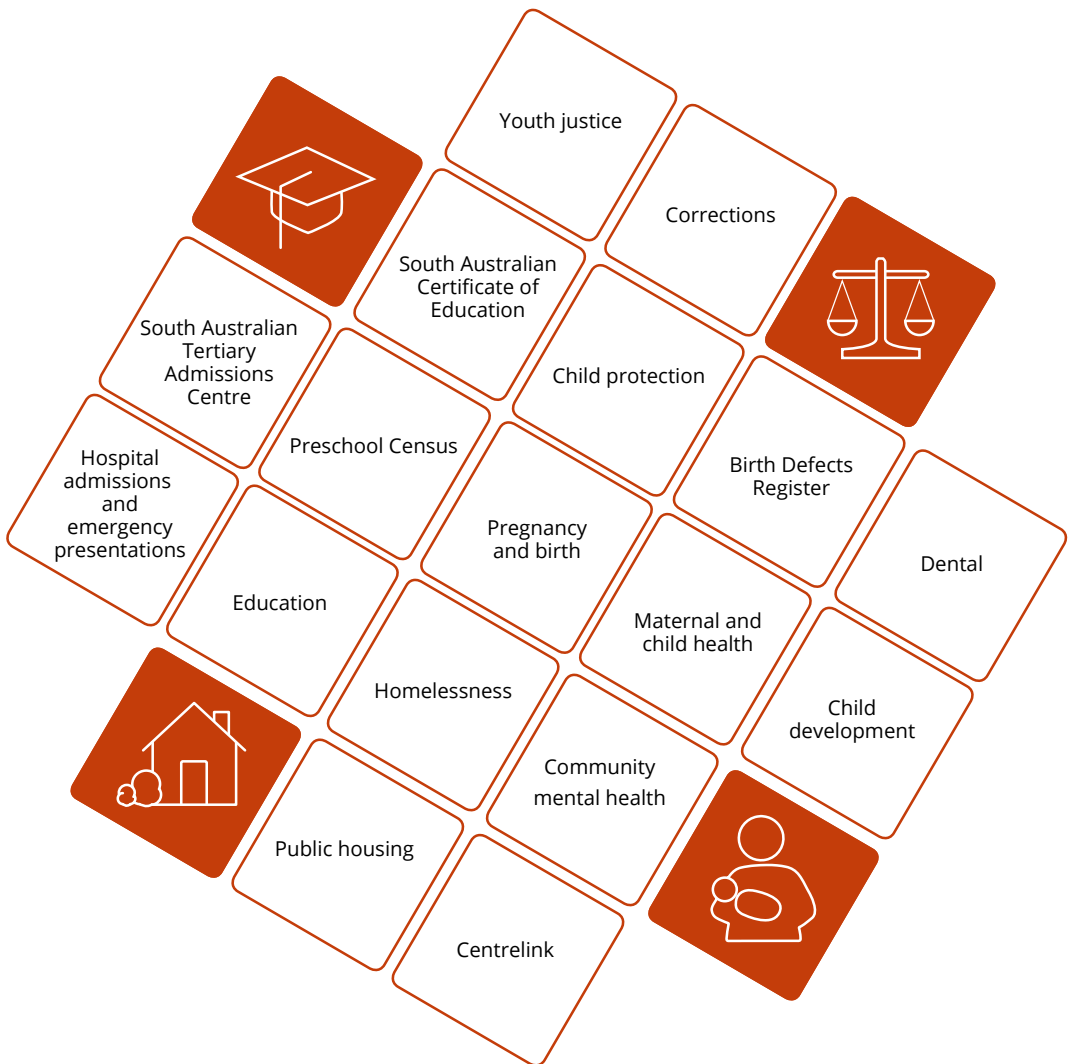
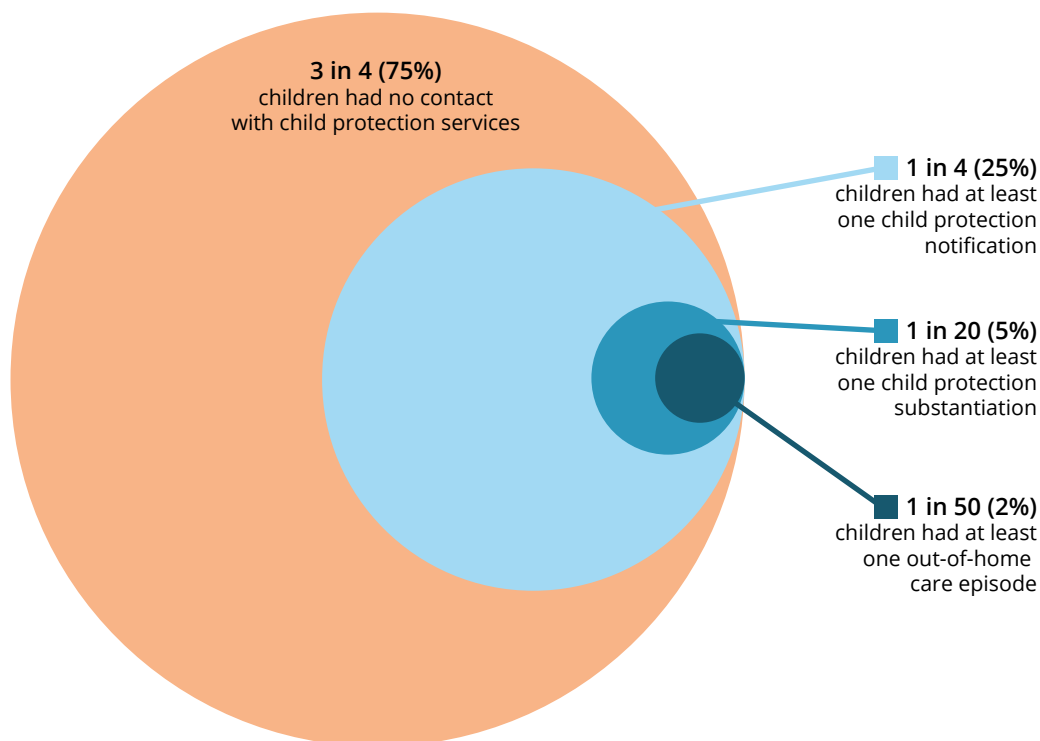# Case study 1: a public health approach to child maltreatment

The 2016 release of the South Australian Nyland Royal Commission (Child Protection Systems Royal Commission 2016) into child protection services provided a context for a better approach to understanding the problem of child maltreatment. We have partnered with the Early Intervention Research Directorate and the South Australian departments of Child Protection, Premier and Cabinet, Health, Education, and Human Services to provide advice and data analytics on multiple questions concerning many aspects of child protection. Research using the SA ECDP has been instrumental in building cross-government consensus and buy-in that child protection is everybody's business.

Until recently, administrative child protection data have been closely guarded and rarely available for systematic research, let alone linked with other government administrative data. The AIHW reported that in 2016–17, 233,795 Australian children were notified to child protection services ('screened-in' notifications), translating to approximately 1 in 25 children aged under 18 being notified in 1 year (AIHW 2019). This represents an increase of 27% from 2012–13. However, due to national reporting practices, the AIHW has been unable to investigate the longitudinal child protection experience for children in Australia. Individual unit record data about child protection have only been made available by jurisdictions for national collation since 2012–13. Prior to this, only aggregate data were provided to the AIHW. The unit record collection since 2012–13 has not been consistently provided by all jurisdictions, which constrains the ability to explore longitudinal child protection contacts nationally.

In South Australia, linked child protection data were used to investigate the basic epidemiology of child protection as the first step in a public health approach. The most basic epidemiological questions are around estimating incidence and prevalence by age. In other words, 'How many children touch the child protection system over their life course?' was the first question of interest. The process of linking data at the individual level turns child protection 'incidents' (contacts with the system) into child protection experiences of individuals over time (in epidemiology, that is called 'incidence'). An incident-based system may struggle to tell the difference between 10 contacts from 10 individuals versus 10 contacts from the same individual. Using linked child protection, births and perinatal statistics data, the child protection experience of children born from 1999 to 2005, from age 0 to 10, was investigated. See Glossary for terms used in child protection in South Australia.

This research demonstrated that 1 in 4 (25%) children were notified to child protection, 1 in 20 (5%) were substantiated and 1 in 50 (2%) experienced some form of out-of-home care (OOHC) at least once by age 10 (see Figure 8.2). To put this into a health context, the cumulative incidence of contact with the child protection system is about 2.5 times that of asthma with the health system, the most common chronic health condition experienced by Australian children (AIHW 2017). The sheer scale of the contact with child protection at young ages strengthens the case that child protection is best seen as a public health issue that requires both effective treatments for those affected, and effective primary and secondary prevention. These patterns of frequent contact with child protection are not uncommon. Other Australian jurisdictions and some overseas countries show similar patterns, although direct comparisons are difficult due to differences in legislation, reporting practices and how reports are coded and processed (O'Donnell et al. 2016; Protecting Victoria's Vulnerable Children Inquiry 2012; Putnam-Hornstein & Needell 2011; Queensland Child Protection Commission of Inquiry 2013; Rouland & Vaithianathan 2018; Zhou 2010). Nevertheless, what is clear is that the scale of the problem of child maltreatment has been vastly underestimated.


Figure 8.2: Child protection system contact by age 10 for children born in South Australia between 1999 and 2005

3 in 4 (75%)
children had no contact
with child protection services

1 in 4 (25%)
children had at least
one child protection
notification

1 in 20 (5%)
children had at least
one child protection
substantiation

1 in 50 (2%)
children had at least
one out-of-home
care episode

Another question of interest was 'What is the developmental profile of these children who have contact with child protection?' Using linked child protection and Australian Early Development Census data, the development at age 5 among children according to type of contact with the child protection system was investigated (Pilkington et al. 2017). Figure 8.3 shows that as the level of contact with the child protection system increases, so does the prevalence of developmental vulnerability on 1 or more domains at age 5. Children who have experienced OOHC are almost 3 times more likely to be vulnerable than children with no child protection contact. It is important to note that these results also show that even children who have only ever been notified (never screened in), and never had any more serious child protection contact, are nearly twice as likely to be developmentally vulnerable at age 5 (approximately 36% developmental vulnerability among children notified compared with 17.7% among children with no contact) (Figure 8.3). This level of increased developmental risk is similar to the differences between the most and least socioeconomically disadvantaged.

Figure 8.3: Proportion of children vulnerable on 1 or more domains of the Australian Early Development Census at age 5 for children born in South Australia between 1999 and 2005, by level of contact with the child protection system
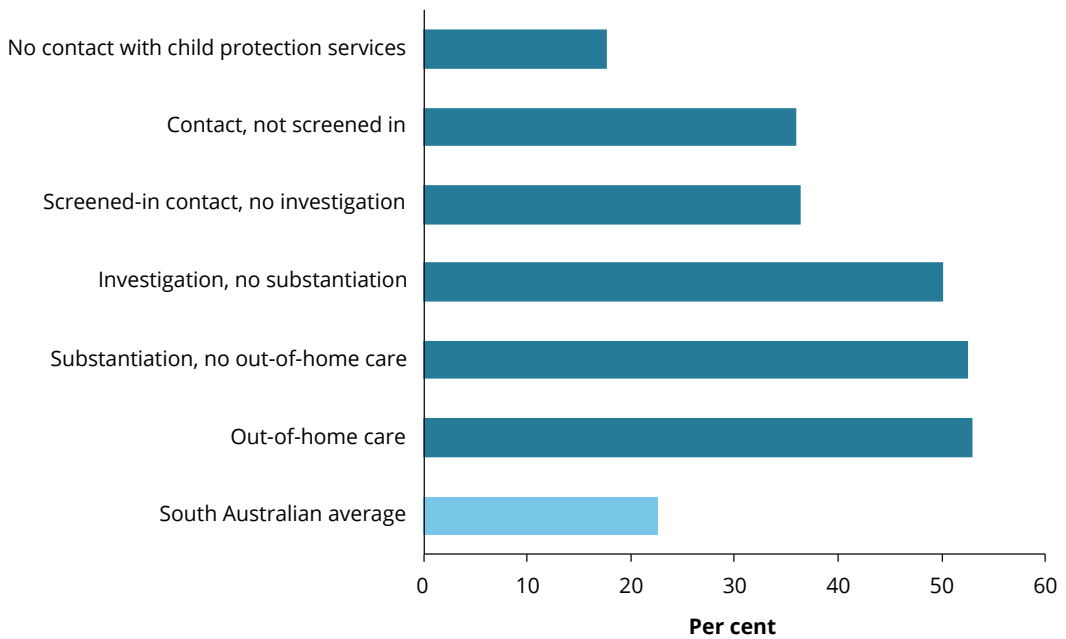
Note: Each category refers to 1 or more contacts with the child protection system at that level.

The results of these analyses, which link levels of child protection contact to developmental vulnerability at age 5, are in stark contrast to anecdotal evidence that many initial notifications are 'not real' and that the '1 in 4' is an overestimate. While, undoubtedly, notifications are made without enough information to enable further child protection investigation, these data show that, on average, notifications determined not to be 'child protection matters' are an indicator of higher risk for poor child development. With national acknowledgment that 'protecting children is everyone's business' (COAG 2009), this also reinforces the notion that child protection requires a whole-of-government coordinated response to address the spectrum of child protection–related concerns and ensure children have the best start in life. These patterns of developmental vulnerability are at age 5—the year these children enter formal schooling.
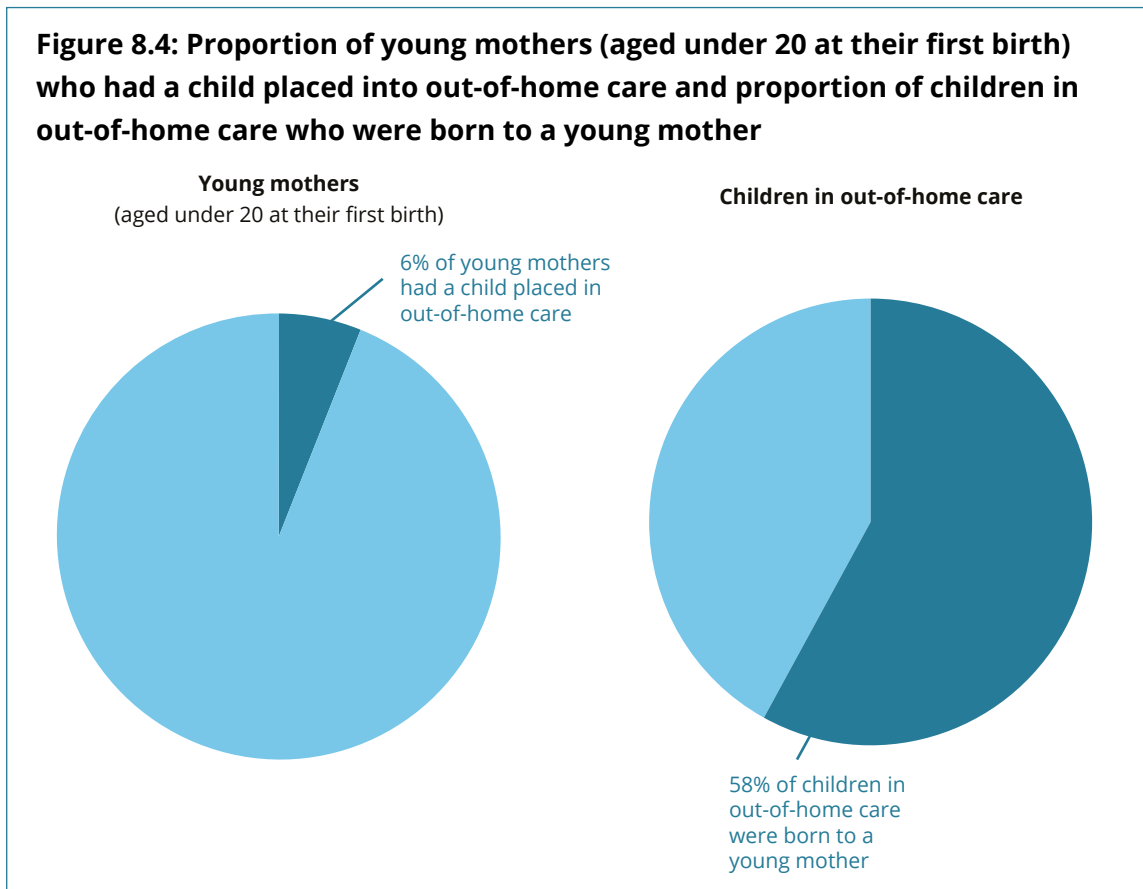
This research has been the subject of widespread media and community engagement in South Australia (Novak 2019). It has been the basis for government-led community consultations, and over 40 presentations to government, non-government and community groups. The social and public health benefit of such widespread public conversations is developed through encouraging consideration of the role of both government and the community in preventing child maltreatment.

Case study 2: describing priority populations with high prevention potential

There has been a longstanding policy interest in young parents and young mothers (defined as mothers aged under 20) for many reasons. In Australia, this is partly related to the significant policy and program focus in the United Kingdom and the United States on reducing teen pregnancy rates (Hadley et al. 2016; Lawlor & Shaw 2002). However, there is growing acceptance that young maternal age in itself does not cause poor health outcomes for infants. Rather, it is the confluence of personal, social and economic disadvantages that are more likely to co-occur with young maternal age that increases risk of poor outcomes (Chittleborough et al. 2011; Lawlor & Shaw 2002). The proportion of births to young mothers in Australia is lower than ever before at under 3% (AIHW 2018), so at first glance, it seems unlikely young mothers contribute substantially to children coming in contact with the child protection system. Understanding both the historical policy interest and the historically low rates of births to young mothers, the South Australian Government wanted to investigate local and current evidence for the association between maternal age and child protection risk using the SA ECDP.

Linked child protection, perinatal and births registration data were used for children born in 1999 to 2013, and followed until the end of 2015, where the mother's first child was born in South Australia (n = 116,051 mothers; n = 208,903 children). We also followed a subset of these mothers over the same period who had at least 1 child placed in OOHC (n = 1,183 mothers; n = 2,053 children).

In Figure 8.4, the 'young mothers' circle focuses only on mothers aged under 20 at their first birth (n = 10,364) and shows only 6% of young mothers had children who were placed in OOHC. However, of all the children who were in OOHC, 58% were born to a mother aged under 20 at the birth of her first child ('children in out-of-home care' circle).

Figure 8.4: Proportion of young mothers (aged under 20 at their first birth) who had a child placed into out-of-home care and proportion of children in out-of-home care who were born to a young mother

Young mothers
(aged under 20 at their first birth)

6% of young mothers had a child placed in out-of-home care

Children in out-of-home care

58% of children in out-of-home care were born to a young mother

In other words, the vast majority of young mothers do not have children placed in OOHC, but of the children who experience OOHC, over half were born to a mother who was young when she had her first child. It should also be noted that 70% of mothers aged under 20 at their first birth had partners aged under 25, so there should be a focus on young parents, not just young mothers.

This demonstrates that a small proportion of young parents are experiencing circumstances that indicate a need for intensive support to help prevent their children being placed into OOHC. It is important to understand this is not about how old parents are, but reflects broader personal, social and economic life circumstances faced by some young parents. Young parents regularly appear in the antenatal and postnatal health system, and assuming they can be engaged in effective interventions, the potential to prevent children being placed in OOHC is high. This research is currently feeding into a whole-of-government strategy on child protection secondary prevention.
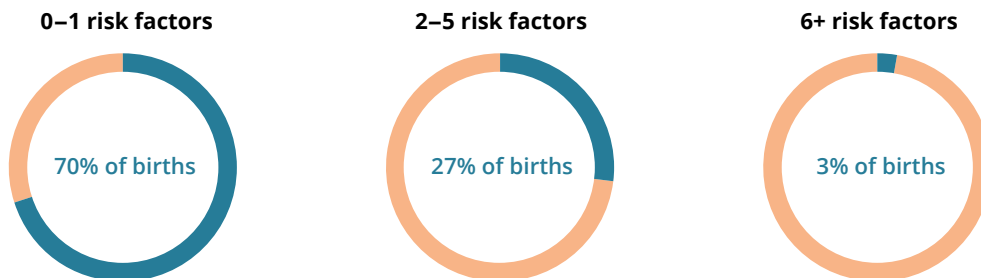
Case study 3: redesigning a model of care

The South Australian Child and Family Health Service (CaFHS) is a backbone agency within the early childhood system that delivers state-wide universal and targeted services with the aim of improving health, development and wellbeing outcomes for South Australian children (CaFHS 2018). Over the past 5 years, the collaboration with CaFHS has evolved from using the SA ECDP to inform a service redesign, to working towards embedding evaluation of innovations in models of care into service delivery, and improving the capture and retrieval of key information on service delivery and outcomes.

The example presented here focuses on how linked perinatal, births registration, housing, CaFHS and child protection data were used to understand different levels of adversity and vulnerability experienced by infants in South Australia (Pilkington & Lynch 2017). This was in the context of the final report of the South Australian Child Protection Systems Royal Commission (2016) pushing for maternal and child health and education agencies to have a greater preventative role in a broader child protection system.

Acknowledging there is no standard definition of what makes a child 'vulnerable' to experiencing poorer outcomes, a combination of socioeconomic, trauma, psychosocial and health-related risk factors were used to estimate levels of risk experienced in each birth cohort born in South Australia. Figure 8.5 demonstrates the distribution of risk factors in the whole population of births in South Australia with an estimate of the average proportion of births each year experiencing different levels of risk. Of the estimated 20,000 births per year, approximately 70% will experience none or 1 risk factor and are likely to require universal services, while 30% will experience 2 or more risk factors, indicating a potential need for more intensive support. Among Aboriginal and Torres Strait Islander communities, these proportions are almost reversed due to the historical forces creating multiple forms of discrimination and adversity that create higher levels of vulnerability (see CaFHS 2018 for more detail).

Figure 8.5: Estimated proportion of births experiencing different levels of vulnerability based on distribution of risk factors

0–1 risk factors — 70% of births

2–5 risk factors — 27% of births

6+ risk factors — 3% of births

Increasing levels of vulnerability

Increasing intensity of service response

This research directly informed the development of the CaFHS' new model of care and, through small-area-based adversity profiling, is also informing resource allocation from lower to higher areas of need based on the absolute number of expected births at different adversity levels. The CaFHS example demonstrates how data linkage across otherwise siloed services can support service design and delivery, by using population-level evidence of the need for supportive, intensive and targeted services.

What are the implications for improving use of linked public data?

Researchers need a new model of partnership with service agencies

Over the past decade, the experience of building the SA ECDP, and partnering with the aim of achieving public good, have shown that the need for public good also speaks to the need to consider how academics work with government and non-government stakeholders. It is clear that knowledge transfer is not a linear, predictable process, where researchers develop ideas, then compile and analyse data which generate new insights that are transferred into policy and practice change with end-user benefit. Developing truly collaborative partnerships with stakeholders entails a substantial investment of time, patience, energy and, of course, buy-in from the relevant stakeholders.

As many jurisdictions develop their internal capacity to link their own data, building linked data resources is no longer a sufficient reason for government to partner with academics. It is now incumbent on researchers to demonstrate value beyond the capacity already available within government. They need to be actively engaged with stakeholders and share commitment to delivering research that actually improves service delivery. For some, this may require a big shift from the way they have worked in the past. The traditional model of academic–government partnerships, where knowledge generation and research translation take over 3 years through some form of stakeholder partnership or linkage grant, is often not fit for purpose in a policy climate of data-driven reform. Instead, partnerships with various parts of government, such as those illustrated in this article, require academics to have the capacity and willingness to respond rapidly to government priorities.
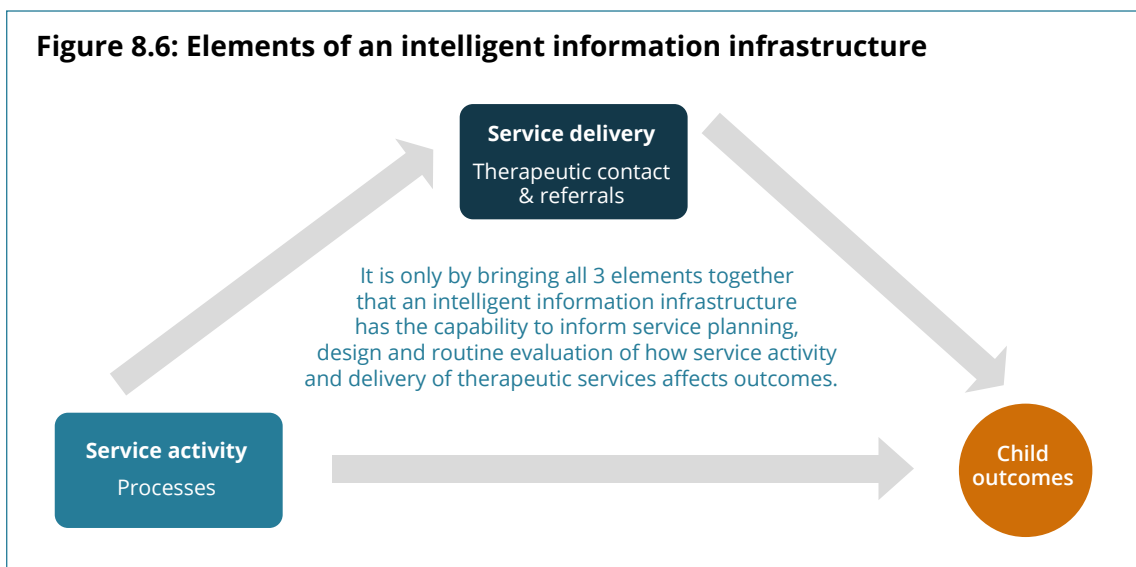
Investing in collaborative partnerships also has significant implications for producing traditional research outputs, raising the question of how universities support these activities as an appropriate role for academics. The conflict between investing in external partnerships and the need for traditional academic outputs poses a challenge for developing a new way of researchers working with government. This is especially the case for early- and mid-career researchers for whom the emphasis remains firmly on building traditional academic profiles. Progress can only be made if universities and funding bodies move beyond the rhetoric of research translation to fundamental reform that may include changes to the way universities are funded to conduct their research. There are encouraging signs with the Australian Research Council's engagement and impact assessment framework (Australian Research Council 2018) which is driving research quality assessments beyond publication and grant metrics. However, this process does not currently influence funding as it does in the United Kingdom (Higher Education Funding Council for England et al. 2014).

There has been some success in knowledge transfer using the SA ECDP because a considerable amount of time has been invested upfront in developing relationships with key stakeholders. A track record of trust and adding value has been established. Successful research translation has included working through a series of deliberate stages that help maximise the value that can be added to the partnership. This involves collaboratively developing the research priorities with an understanding of what data (if any) are available to answer questions of interest. Some of the most difficult aspects relate to defining what the question is. Helping partners clearly articulate what it is they want to know can be a surprisingly challenging task. The challenges that follow include undertaking methodologically rigorous epidemiological analysis with attention to transparent numerators and denominators, and windows of risk. Next is to work through an iterative process with partners to develop a product that communicates the research in a way that empowers end users to understand its significance. In short, epidemiological analysis is used to tell stories with numbers so that non-expert users can interpret and understand the implications of the research undertaken and findings.

Building an intelligent information infrastructure

The child health and welfare field currently lacks a coordinated data infrastructure. The deployment of purposely designed system-wide data infrastructure—which captures system processes and activity, service delivery, therapeutic contact and dose, referrals and referral follow-up (that is, 'warm handover'), and child- and family-centred outcomes—would greatly enhance the capability to understand the impact of government investments. There is no shortage of potential data sources, but how these are used and integrated to help solve problems is not always at the forefront. The goal should be to create an 'intelligent information infrastructure'.

Figure 8.6 illustrates 3 key elements of an intelligent information infrastructure. Currently the SA ECDP holds a lot of administrative data on diverse service processes and activities, from the number of notifications received or the number of home visits to children attending preschool. It also has some high-quality data on outcomes, such as the Australian Early Development Census, child protection contact and the use of public housing. The biggest gap in the data platform concerns actual service delivery. To what services were people referred, did they attend, and what therapeutic dose of any support program did they receive? There are many reporting mechanisms that provide a snapshot of the current state of child health and development outcomes, but we are often left to ponder why outcomes got better or worse. What makes the elements of this data infrastructure intelligent is that they are joined up. Without linking those outcomes to service activity and delivery, we can only guess whether service innovation improved outcomes.

Figure 8.6: Elements of an intelligent information infrastructure

Service delivery
Therapeutic contact & referrals

It is only by bringing all 3 elements together that an intelligent information infrastructure has the capability to inform service planning, design and routine evaluation of how service activity and delivery of therapeutic services affects outcomes.

Service activity
Processes

Child outcomes

Building an intelligent information infrastructure would enable better and more coordinated targeting of scarce resources with the capability to conduct routine evaluations using quasi-experimental methods (Lynch 2017). Bringing together administrative data that include the whole population allows both intervention and appropriate comparison groups to be identified in the data, which is key to using such methods. Additionally, with consent, this data infrastructure could provide the opportunity to follow participants of longitudinal cohort studies and pragmatic randomised controlled trials over long time periods. This would increase insights into 'real-world' outcomes not often available in the time frames supported by limited funding. Of course, all these benefits need to be based on appropriate processes to protect the privacy and security of individuals' data. In our case, the SA ECDP uses only de-identified data, or when special data collections are added, the participants have given specific consent to have their data linked. In both cases, these processes are under strict ethics approvals, reporting and monitoring.

The opening up of data sources across Australia and the growing recognition of the value of linked data represent an opportunity to inform and evaluate innovative approaches to intractable social problems, such as child maltreatment, while preserving confidentiality and privacy. While creating renewable and intelligent data platforms is clearly desirable, it requires suitable funding arrangements. National funding structures are still largely locked into 'one-off' funding processes as discrete projects that are created and then dissolved. The challenge is to change this funding structure to foster sustainable, purpose-built linked data platforms around the country. Without a strategically designed and appropriately funded system-wide intelligent information infrastructure, there will be limited ability to measure the success of whole-of-system investment to improve health and welfare outcomes for families and children in Australia.

Further reading

For more information on the BetterStart Child Health and Development Research Group, see the BetterStart website at health.adelaide.edu.au/betterstart, which includes reports on Child Protection in South Australia and the SA ECDP, along with a short video www.youtube.com/watch?v=-s-9jmNlXIo, describing our research. A South Australian Government research report encompassing BetterStart's partnership with the Early Intervention Research Directorate can be found on the South Australian Department of Human Services website at dhs.sa.gov.au/services/early-intervention-research-directorate.

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South Australian Government

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- Department for Child Protection
- Child and Family Health Service, SA Health
- Data and Reporting Services, Department for Health and Wellbeing
- Prevention and Population Health Branch, Department for Health and Wellbeing
- Women's and Children's Health Network, SA Health
- Early Intervention Research Directorate, Department of Human Services
- Youth Justice, Department of Human Services
- Strategy and Performance, Department of Human Services
- System Performance, Department for Education
- Early Years and Child Development, Department for Education
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