

22 May 2016

Commissioners Jonathan Coppel and Julie Abramson
National Education Evidence Base
Productivity Commission
Locked Bag 2, Collins St East PO
Melbourne VIC 8003

Dear Commissioners

The Telethon Kids Institute has a strong track record in research, evaluation and implementation related to improving child development outcomes in the early years. It was a key partner in the adaption and piloting of the Early Development Index in Australia, and its subsequent national dissemination as the Australian Early Development Census.

Through its WA Child Health Survey and the seminal WA Aboriginal Child Health Survey, the Telethon Kids Institute has provided the evidence and recommendations for many child health initiatives. It also has a proud history of advocacy, having lobbied for services through education and health, contributing to the various models of family, child and parent centres and visiting midwife schemes.

In addition, the Telethon Kids Institute, in partnership with 14 State government agencies, has set up one of the largest linked data capabilities in Australia, and arguably, the world. This capacity links data from the majority of the health, education and social service agencies in WA, to enable research, monitoring and evaluation of children's outcomes across a number of domains (i.e. health, education, child maltreatment, mental health, disability, justice and housing). Some data were collected in the 1960s, with the majority collected since 1980 for individuals born in WA.

The Telethon Kids Institute has always worked closely with community and service providers to both frame the research approach and translate research findings into policy and practice. This approach is entrenched in the Institute's strategic plan: Working Together 2013-2017 and described in a number of programs in its IMPACT report.

In December last year the Telethon Kids Institute and Minderoo Foundation launched the Early Childhood Development and Learning Collaboration. The Collaboration is bringing together leading educators, clinicians, community and researchers to improve service delivery to meet the needs of vulnerable children, families, and communities. It will help to fast track research into action to improve outcomes in the crucial early years of child development and learning.

The Early Childhood Development and Learning Collaboration has four overarching aims to:

- conduct new and original research;
- interpret existing research findings in varying contexts;
- translate this research into practice through demonstration projects; and
- connect this research translation to communities and the policy arena.



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Telethon Kids is pleased to provide a response to the Productivity Commission Issues Paper on the National Education Evidence Base. In particular, the Institute has addressed the following sections in the Paper:

- Scope of the inquiry;
- Determinants of education outcomes;
- Framework for a national evidence base; and
- Data sharing.

General Comments

Together with Early Start (University of Wollongong), the Life Course Centre, Minderoo Foundation, Mitchell Institute and Murdoch Children's Research Institute (MCRI), the Telethon Kids Institute acknowledges the Commission's efforts to identify the main issues related to this Inquiry into the National Education Evidence Base. The Institute congratulates the Commission and its staff on its comprehensive summary of the subject matter and the succinct manner in which it has been communicated.

In our submission we have drawn on the experiences and expertise of researchers from across the Telethon Kids Institute as well as colleagues from Early Start, the Life Course Centre, Minderoo Foundation, Mitchell Institute and MCRI to provide comment on the issues these researchers believe are the most significant regarding the development of a national education evidence base.

Scope of the inquiry

Does this interpretation of the scope of the terms of reference accord with yours?

Yes.

In particular, should the scope of the evidence base include data on children younger than 4 years old (or prior to the year before compulsory schooling begins)? If so, why, and should it cover all children, or only those attending early childhood education and care programs outside the home?

Telethon Kids Institute recommends the evidence base include data from all children from the antenatal period onwards.

The evidence base demonstrates that the basis of a happy, healthy and productive life is laid down in utero and in the first three years of life (Center on the Developing Child, 2010, Royal Australian College of Physicians, 2006, Silburn et al., 2011, McCain et al., 2007, Center on the Developing Child, 2007). "Virtually every aspect of early human development, from the brain's evolving circuitry to the child's capacity for empathy, is affected by the environments and experiences that are encountered in a cumulative fashion, beginning early in the prenatal period and extending throughout the early childhood years" (Phillips and Shonkoff, 2000).

The quality of the home environment is the most important factor in a child's social and intellectual development, (Harrison et al., 2010, Belsky et al., 2007) even eclipsing poverty (Kiernan and Mensah, 2011). Australia has no measures on the quality of parenting or family cohesion. Capturing data on the most significant determinant of children's educational performance and social and emotional development would be a worthwhile inclusion in the national education evidence base (Harrison et al., 2011).

Quality early childhood education and care has been demonstrated to improve outcomes for children, particularly those who are disadvantaged (Belsky et al., 2007, Burger, 2010). Early childhood education and care includes playgroups as well as licensed long day care (Harrison et al., 2011). Both have positive effects on early childhood development (Hancock et al., 2012, Belsky et al., 2007). Data available from this sector should be included in the national education evidence base.

Where possible, the evidence base should include data on children of all ages. As educational data will not be available for children who do not attend licensed long day care services, the ability to link data that is available prior to their enrolment in school will be important. These data are most likely to be maternal, paternal, infant and child health data as well as environmental and community data. It is important that the child assessments administered during school enrolment be improved, particularly for those children for whom there are limited data from earlier in their lives. These children are also more likely to be from the most disadvantaged families. The types of information to be recorded should, where possible, encompass their attendance at early childhood education and care programs (including playgroups), parenting programs, health data including birth outcomes, and demographic data including family composition. The inclusion of a measure of school readiness would also be useful.

Determinants of education outcomes

Do you agree that the objective of a national education evidence base should be to improve education outcomes? Are there other objectives that should be included?

Telethon Kids Institute suggests that the government makes its objectives more explicit, visionary, and achievable and these have a dual focus addressing the benefits for individual children and the nation as a whole. The evidence base should be embedded within the context of a child outcomes framework (using a program logic approach), including a specific focus on vulnerable children.

The national education objectives are not explicitly stated in the Issues Paper however "some key documents" are referenced, namely the *Melbourne Declaration on Educational Goals for Young Australians*; the *National Education Agreement*; and the *Early Years Learning Framework*.

- The Preamble to the *Melbourne Declaration* provides context and alludes to the higher level policy objectives of the education system.
- The objective of the *National Education Agreement*, namely "that all Australian school students acquire the knowledge and skills to participate effectively in society and

employment in a globalised economy”, is focused on school students. It is missional in nature rather than a visionary objective of the purpose of education.

- The vision articulated in *COAG’s Investing in the Early Years - a National Early Childhood Development Strategy* is aspirational and focused on the early years: “By 2020, all children have the best start in life to create a better future for themselves and for the nation”. It references the following policy objectives:
 - Greater social inclusion;
 - Improved outcomes for the majority of children but specifically Indigenous children and the most disadvantaged; and
 - Increased productivity and international competitiveness.

The national evidence base as described in the Issues Paper is a network of datasets. They can measure changes over time, provide insight into drivers and inform policy decision making, service delivery and evaluation. Of themselves, however, these datasets have no power to improve education outcomes.

Telethon Kids Institute recommends that a program logic approach be applied to developing a child outcomes framework with the child at the centre. A program logic approach provides a chain of reasoning and a theoretical model for defining the interrelated components of a project that are required for its success. A program logic will:

- ensure that the objectives and outcomes are made clear;
- make explicit the causal pathways and the link between objectives, inputs, activities, outputs and outcomes (short, medium and long term);
- nominate measures against each of these including identifying the existing datasets and their measures;
- provide a framework for evaluation;
- map the impact of external and internal determinants; and
- identify how the system can respond to external determinants. These external determinants can reinforce educational outcomes (both positive and negative) across generations (Hancock et al., 2016).

Including a set of guiding principles would be helpful. Both of the frameworks referenced below contain guiding principles which underpin them.

Two interrelated bodies of work can help to provide a broader framework into which the educational datasets could be incorporated (for further detail refer to Appendix A). This will mean that rather than adding a new framework to those already in existence, the strengths of these can be leveraged and their scope potentially expanded to include more detail on education from early childhood through to Year 12. These are:

- ARACY’s *the Nest* (National Action Plan for Child and Youth Wellbeing) ages 0-24 years; and
- The Opportunity Child / Centre for Social Impact’s proto-type of a shared outcomes framework 0-8 years which uses *the Nest’s* domains as its foundation (Telethon Kids Institute, the Murdoch Children’s Research Institute and ARACY were commissioned to undertake this work).

While *the Nest* addresses the needs of all children, it places a particular focus on the needs of vulnerable children. *“Investing in disadvantaged young children is a rare public policy initiative that promotes fairness and social justice and at the same time promotes productivity in the economy and society at large” (Heckman, 2006).*

What education outcomes do you see as relevant? For example, outcomes in traditional academic domains (such as literacy and numeracy), outcomes in non-cognitive domains (such as communication and interpersonal skills).

Telethon Kids Institute recommends the Commission employ a broad definition of outcomes. Outcomes should include non-cognitive outcomes such as health and social and emotional development and early childhood development. This will require linkage with datasets outside of the education sector.

Children and young people experience life holistically with education forming an important component. This is shown by Bronfenbrenner’s ecological model of childhood development which helps to graphically represent the integrated lives of children as a systems model (Bronfenbrenner, 1979).

Schools do not act in isolation. The data generated to understand the performance of the education system and students is deeply affected by the ‘external determinants’ referred to in the Issues Paper. Evidence suggests these external determinants may be **more** important than school factors in terms of their contribution to academic outcomes (Emerson et al., 2012).

Despite its demonstrated importance to academic outcomes, Information on the social and emotional development of Australia’s children and young people is limited (Australian Research Alliance on Children and Young People (ARACY), 2014). One of the key contributors to children’s social and emotional wellbeing is family functioning, yet no national data are collected that measure children’s perceptions of family functioning (Australian Research Alliance on Children and Young People (ARACY), 2014, Australian Institute of Health and Welfare (AIHW), 2007).

Multiple events and circumstances typically propel children towards educational and social failure (Jenson and Fraser, 2011). Comprehensive, linked data are instrumental to understand these external determinants at a population level and inform the development of appropriate policy responses. Prevention, early intervention and treatment interventions are all required. At the school level, understanding the needs of individual students will enable the school to support these children appropriately.

Shifts in outcomes at the population level will occur when the majority of children are moved along the trajectory in a positive direction. The AEDC results for 2015 (Department of Education and Training, 2016) indicate that 22% of Australian children are developmentally vulnerable on one domain, while the percentage of children vulnerable on two or more domains has been around 11% since data were first captured in 2009. This percentage has not shifted over the previous three years. In addition, those on the cusp of vulnerability require assistance to avoid falling further behind.

Framework for a national evidence base

What data should be collected nationally?

The current reliance on AEDC and NAPLAN data has limitations. The AEDC, is a cross-sectional population level tool. Individual children cannot be tracked over time in all jurisdictions for AEDC and NAPLAN. Further, if children are absent on the testing day their results are not included. Depending on the child's circumstances on the day, their mood and the level of pressure they experience, their performance may not be representative of their actual literacy and numeracy levels. The recently released Grattan Institute paper suggests an improved method for reporting on NAPLAN results that focuses on 'years of progress' rather than raw test scores (Goss et al., 2016, Goss, 2016).

The Issues Paper acknowledges that Tasmania provides student-level data to the ABS. Tasmania's integrated approach enables children to be tracked from their engagement with a Child and Family Centre through the school system. It also includes health data from pregnancy and birth throughout childhood. This integrated system provides longitudinal data that includes both education and health outcomes.

The Developmental Pathways in WA Children Project and the Data Linkage Branch allow for WA children to be tracked from birth, and pre-birth, over their life-course. WA has the ability to link parents to children, as well as siblings, allowing researchers to look at family, individual and community level factors which influence children's education (and other) outcomes.

As noted above, the absence of data measuring children's social and emotional development is a significant gap.

How would these data support the objective of improving educational outcomes?

As noted above, the assumption that data alone can improve educational outcomes is flawed. These data can provide insight into causal relationships and correlations and can be used to inform policy development, service delivery, monitoring and evaluation.

What characteristics should the data possess to support the processes of monitoring progress, evaluating policies and programs and/or informing policy development?

There is a need for longitudinal data that are identifiable, to enable linkage across multiple datasets. Additionally, there is a need to capture and analyse data in real time.

To support the processes of monitoring progress, evaluating policies and programs and/or informing policy development, the data need to provide population level data as well as information that explains the trends (this information is usually collected through case studies) as well as be:

- Valid and reliable;
- Accurate;
- Complete;
- Consistently measured across jurisdictions; and
- Able to be linked through a unique identifier.

In respect to unique identifiers, a statistical linkage key (SLK) is not sufficient to enable good quality, robust linkage. Data should include as much information as possible to inform (including name, address and date of birth) as there are often errors in point of collections, leading to incorrect SLKs. These errors lead to incorrect or missing matches when linking data. Having full identifying information reduces the likelihood of this error. There are many ways that linkage can be achieved, using identifying information that protects individual privacy.

Longitudinal data are necessary to ensure that changes over time can be identified. In WA, the data available through the WA Data Linkage System extend to 1966.

Real time capability is essential. Because it can take up to two years to access data, this lag limits the data's currency and therefore timely contribution to policy development, evaluations and service delivery. Telethon Kids Institute recognises the difficulties in achieving a balance between timeliness and analysis.

Which aspects of administrative datasets are likely to be most useful to inform policy development?

As noted above, real time data availability is essential.

Administrative datasets collect information on demographic characteristics of children and their families, service provision and bio-medical information. There is potential to link these data to other datasets to understand causal mechanisms for particular outcomes. Potential questions that could be answered include dosages required to effect outcomes across particular sets of variables, the equity of service distribution, access rates and characteristics of families and children who access services and to what amount.

At the population level, administrative data can be useful to inform the design of surveys to provide deeper insight. Designing surveys without reference to these data, and/or without the skill sets necessary can result in data that may not be able to be used for research purposes as it cannot be linked to other data or is missing key information.

What costs are associated with collecting and administering the data?

At present, services bear a significant, hidden cost in association with data collection. Funding for this work is generally not built into government contracts however, failure to produce the data can result in contractual penalties or even termination. This lack of resourcing is particularly acute in the early childhood education and care sector which operates on tight margins and generally has limited administrative support compared to schools.

Another major cost are the service fees levied by government departments for access to their data by research organisations. The fees can be prohibitive and may not be based on the actual costs incurred.

Issues and opportunities

What are the main challenges and impediments to implementing data linkage in the education sector? Are these challenges and impediments different from other sectors? If yes, how?

Within the early childhood education and care sector, there are a number of opportunities:

- Existing data can be better linked
- Existing data collections can be updated to provide greater detail at the individual level
- Improvements under the National Quality Framework can be better analysed and reported and
- Capabilities of the sector in data collection and use can be enhanced.

With the notable exception of data measuring social and emotional development, there is a large amount of education data currently available. Some key datasets that could be more effectively linked include:

- Early childhood data
 - AEDC
 - Data drawn from the Child Care Management System used to administer existing child care subsidies (Child Care Benefit and Child Care Rebate)
 - Administrative data from licensed long day care services, family day care services and playgroups (much of which feeds into the Child Care Management System)
 - Data drawn from the new IT arrangements under the Jobs for Families Package once fully implemented in July 2018 (Child Care Subsidy and the elements of the Child Care Safety Package: Additional Child Care Subsidy, Community Child Care Fund, Inclusion Support Programme)
 - Data on the assessment and rating of licensed long day care and family day care services
- Data from the Department of Social Services
 - Data from Family Tax Benefits A and B
 - FOFMS (and its replacement) used by the Department of Social Services to record information on services it contracts out
 - Requiring the data currently collected by the Department of Social Services through its Data Exchange (DEX) (Department of Social Services, 2016a) to be linked to other key datasets rather than only being used internally
- Medicare data

Where existing data collections do not allow information on individuals to be captured, these should be updated to enable greater granularity. For instance, data on grant programs administered by government departments are unlikely to capture which children and families are being supported. The impact of these programs is therefore hard to establish. Also, the reporting mechanisms vary widely with little information captured that can linked to other data sets. Often, the data required are changed making performance over time difficult to measure.

Data captured on services' assessment and rating under the National Quality Framework are currently aggregated. Ensuring that educational and social and emotional wellbeing data on individual children are linked to the rating and assessment of services they attended would provide a useful mechanism to demonstrate the impact of high quality services.

At the individual service level, there is a high potential for variability in the way data are collected and used. The accuracy and completeness of data will depend on skill levels, individual biases and work pressures of staff completing administrative forms. The availability of staffing and administrative support will also have a significant impact on the data quality. The early childhood sector is generally more poorly resourced than schools, and often employ staff with lower levels of skills (eg: a Certificate III rather than a minimum 3 year degree). As noted above, playgroups, parenting and community support programs are seldom funded for administrative support which is essential to collect the data. Thus the ability of the early childhood sector to collect data are currently limited by both capability and capacity.

All approved child care services must use a system that links to the Federal Government's Child Care Management System (CCMS). The number of individual software packages approved for use with CCMS totals thirty (Department of Social Services, 2016b). In designing the national education evidence base it would be prudent to focus efforts on linking data with CCMS rather than the individual software packages which would necessitate linking data from each licensed long day care and family day care provider.

A major impediment to the establishment of a national education evidence base is the absence of infrastructure for data to be usefully integrated. There is a plethora of datasets however, the challenge is that there is currently no means for central collation and storage.

In designing the national education evidence base it is important to ensure that the focus does not become compliance and accountability at the expense of policy development and service improvement (Nous Group, 2014). A fixation on compliance will increase paperwork, decrease innovation and entrench the climate of fear and retribution that has been occasioned by the introduction of one-off tests that do not take account of external determinants (eg: NAPLAN).

Data sharing

What lessons can be learnt from previous data linkage efforts, in the education and other sectors (e.g. health care, social services) and from other countries?

The recognition that establishment of data linkage can take considerable time and succeed largely through positive relations is supported in this submission.

Telethon Kids Institute's experience with accessing and using educational data

Telethon Kids Institute has significant experience with the processes required to access and use educational data across all states and territories. There are two major bottle necks: a) the ethics approval process and b) the need to obtain data custodian approval.

The need to obtain ethics and access approval from each state/territory department of education, Catholic Education in each jurisdiction (and individual Catholic schools in some jurisdictions) and independent schools is time consuming. The ethics requirements of each jurisdiction's various

education bureaucracies are different meaning that each application can require up to 24 versions to satisfy each sector and jurisdiction.

Obtaining data custodian approval is also problematic. There may be a lack of trust between departmental staff and researchers about how the data will be used. Education bureaucracies are risk averse to the release of data. In some instances, parental agreement to participate and release the necessary data has been overturned by the bureaucracies. WA has a formal Intellectual Property Agreement that requires all researchers making use of its linked data to provide custodians with copies of all reports prior to their release. Custodians have two weeks to review the reports (for further detail refer to the section below on the WA Data Linkage System). The introduction of national guidelines mandating governance mechanisms for how data is shared and publications released could help to improve the current situation.

Further detail on researchers' experiences with data linkage can be found in the submission lodged by the Life Course Centre, particularly related to their experience with linking the Young Minds Matter survey data to NAPLAN data. Their submission provides a recent example of the challenges associated with linking educational data within and across jurisdictions and educational systems (state, Catholic and independent).

Western Australian Data Linkage System

The creation of a data linkage system...demands leadership, interagency and inter-sectoral cooperation, a dedicated group of users who drive reforms, and perseverance. It is the relative scarcity of these community resources that explains why comprehensive, population-based data linkage systems are so few in the world today. The requirements for technological solutions and resources are overshadowed by the importance of high-quality relationships between leading individuals and between institutional players. These relationships have assisted in development of best practice protocols and procedures to address privacy concerns and in disseminating research results more broadly in support of the public good (D'Arcy et al., 2008).

Western Australia has a strong history of data linkage, and has long been a leader across Australia and around the world. Western Australia has longitudinal data for over 3.7 million people dating back to the 1960s-1970s. The ability to link data at a unit record level is a noteworthy characteristic.

The Western Australian Data Linkage System (WADLS) was established in 1995 as a collaboration between the WA Department of Health, the Telethon Kids Institute, the University of Western Australia (UWA) and Curtin University (D'Arcy et al., 2008, Stanley et al., 2011).

The WADLS has evolved into a large and complicated system, which now includes over 40 years' worth of data from more than 40 collections across the health, education and welfare sectors. It also includes genealogical information to enable linkage of family groups and spatial information (for full details of its coverage, please refer to Appendix B and also www.datalinkage-wa.org.au/data-collections/other-data-collections). The expansion and extension of the WADLS to enable innovative cross-jurisdictional data linkage has created a powerful and unique research and policy planning and evaluation resource for use by researchers and decision makers.

A number of factors have contributed to the successful establishment and ongoing operation of the WADLS, and these are described below.

The WADLS was built on strong, and often pre-existing, relationships, as many of the people involved already knew each other. Over time, those involved were able to develop links and establish mutual understanding between the research sector and State and Commonwealth bureaucracies, with many senior leaders having worked across these sectors.

Furthermore, the WADLS was underpinned by diverse sources of financial support. The WADLS receives funding from multiple streams, including government, university, philanthropic and fee for service work. An initial grant to establish a data linkage unit at UWA was also instrumental in establishing the necessary capacity.

The WADLS has attempted to balance open access with control of data through a number of key protocols and policies. Government agencies retain control as data custodians and provide data extracts. The trade-off, however, is timeliness. The Data Linkage Branch (DLB) grants access to any bona fide researcher with a WA collaborator, who has obtained approval from the relevant data custodians, and the relevant Human Research Ethics Committee(s) (for copies of the relevant access and use policies please see www.datalinkage-wa.org.au/policies). Furthermore, as mentioned previously all papers prepared using linked data are provided in draft form to data custodians prior to publication, with custodians given two weeks to review and provide feedback.¹ The WADLS also developed a best practice linkage protocol for data sharing between WA and Commonwealth owned datasets.

The creation of supportive infrastructure, such as the Data Linkage Branch, also contributed to the success and longevity of the WADLS. The DLB has been located within the WA Department of Health since inception, which overcame some issues to do with privacy and access to data, as well as giving the parties involved a sense of ownership of the data. The DLB is comprised of a client services team, which manages linkage projects and assists research applicants to obtain linked data; a data linkage unit, which performs the linkage and provides systems support; a systems support team, which provides technical support; and an analysis and quality team, which undertakes special projects including the WA Family Connections Project and WA Road Safety Project, and manages, operates and maintains the Custodian Administered Research Extract Server (CARES) (D'Arcy et al., 2008).

Community goodwill and trust, based on past successes, has also been integral to the success of the WADLS (see Appendix C). In recent years, community attitudes have shifted, so that privacy is less of a major concern. Consumer advocates have been meaningfully involved for many years, and as a result strongly advocate for data linkage to improve services and outcomes for WA citizens. There has also been regular and consistent coverage of data linkage in the popular press.

¹ The Intellectual Property agreements state that
All publications shall:

- a) acknowledge the participation in the conduct of the research of parties that contributed but were not co-authors;
- b) publicly disclaim approval or endorsement of the published material as an expression of the policies or view of the Government of Western Australia or any individual Department – unless the Department deems it to be a policy statement; and
- c) not publish any report that is likely to identify clients, staff or facilities of a Department, contains factual inaccuracies or is deemed to be a security risk.

There have been several more recent developments to ensure the continued progression and improvement of data linkage in WA. These are briefly discussed below.

The Developmental Pathways in WA Children Project (DPP) has contributed to the expansion and extension of the WADLS by facilitating the linkage and regular updating of a number of non-health administrative data collections. It is important to note that linkage between datasets held by separate agencies not only provides valuable cross-agency data to answer important and complex research questions, but also contributes to the quality of each of the contributing data sources.

The Data Linkage Strategic Directions Group was established in 2015 to guide and plan the continued progression and improvement of data linkage in WA. The Data Linkage Strategic Directions Group is comprised of representatives from each relevant government agency, WA universities and the Telethon Kids Institute, and also includes the Chief Scientist of WA and the WA Government Chief Information Officer (a recent appointment, and one which reports directly to the Premier of WA).

A new Data Linkage Expert Advisory Group has just been announced. It will be chaired by WA's Chief Scientist. The Group will review the state's "strengths and capabilities in data linkage, the barriers to data linkage, and the processes, governance and funding arrangements. It will consider the current and future requirements for data linkage in WA and provide both short and longer-term recommendations to meet the growing demand and increasing scope for data linkage and to enhance the next generation of whole-of-government data linkage for WA". For further information see: <https://www.dpc.wa.gov.au/Consultation/Pages/Data-Linkage-Review.aspx>

Developmental Pathways in WA Children Project

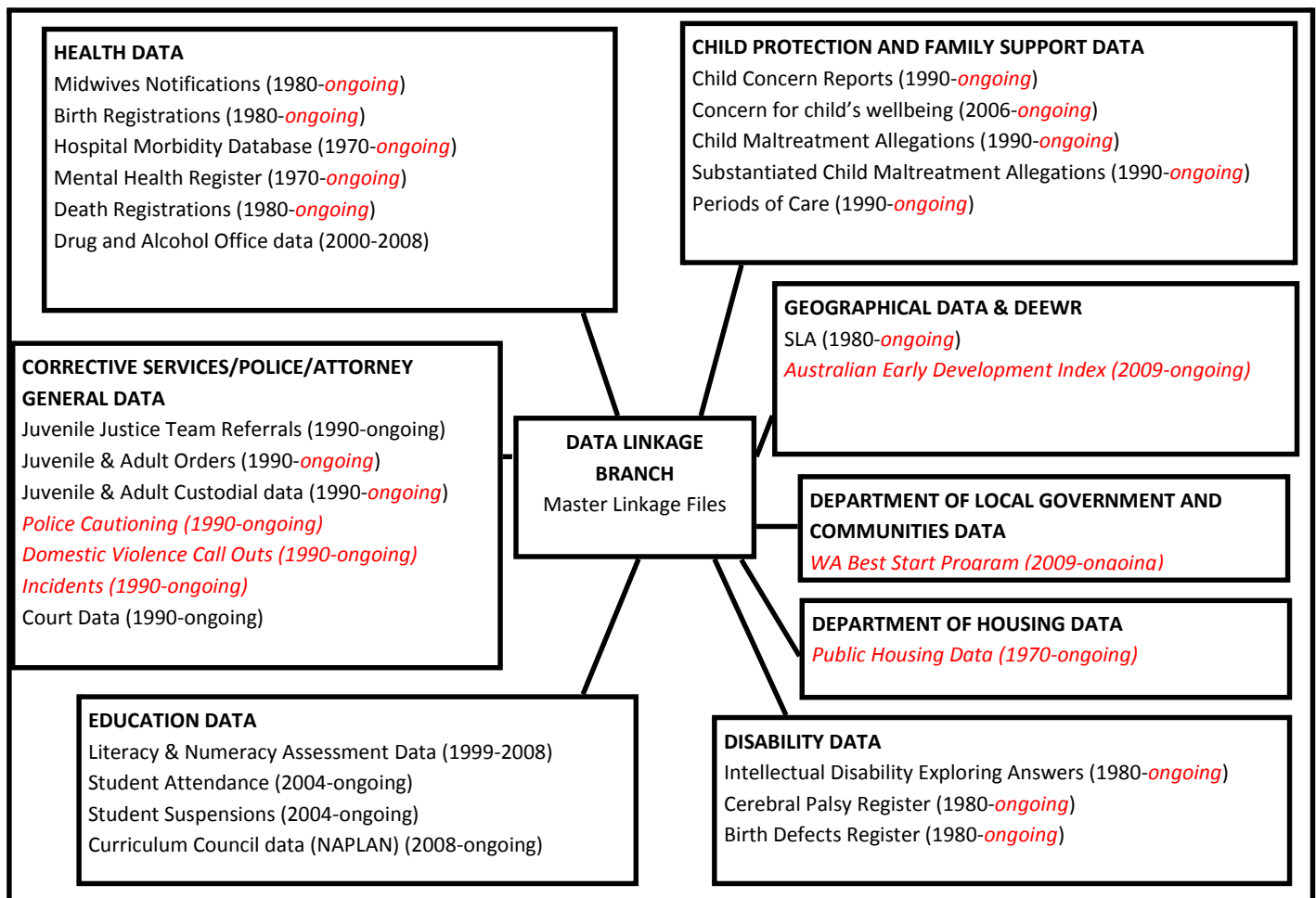
In 2005, the Developmental Pathways in WA Children Project (DPP) was founded at the Telethon Kids Institute, in collaboration with the WA Department of Health and several other State government agencies. The DPP was established to create and maintain the infrastructure linkages of non-health administrative data collections to the WADLS. With the WA Department of Health, the DPP pioneered the process of linking together de-identified longitudinal, population based data collected and stored by a large number of WA government departments, including the WA Department of Education, and the Telethon Kids Institute. To date, the DPP has enabled the incorporation of population data assets from education, disability, mental health, child protection, courts, police, housing, and corrective services to the WADLS.

This work has been funded by two consecutive linkage grants from the Australian Research Council (ARC), with additional cash and in-kind contributions provided from the partner agencies. However, moving forward a more sustainable, long-term funding source is required.

The complexity of many of the health and social issues facing Australian children and youth has led to growing recognition of the need for joined-up data to guide joined-up policies. Traditional datasets held by one agency may fail to identify crucial outcomes. Further, the most effective interventions may lie outside the agencies that have the major responsibility for managing them. There is also growing interest in the importance of the social determinants of health, and how data from the social sector can be analysed to understand complex problems.

Cross-agency data linkage, largely facilitated through the DPP, has encouraged agencies to work together through the safe sharing of information and data. The linkage of non-health datasets has allowed researchers to identify risk factors and monitor outcomes across a range of domains, including educational achievement, to answer complex cross-agency questions. This research is ultimately used to influence government policy and practice to improve the health, wellbeing and development of children and youth, as well as their families and communities.

Data available through the Developmental Pathways Project



* Note text in black represents established linkages, and text in red (italicised) represents planned linkages.

The DPP's strong governance structure and engagement of all relevant government agencies has been integral to its success. The DPP works closely with 14 State government agency partners and is governed by several inter-agency groups. The governance structure ensures maximum communication across all levels, and is comprised of a Directors' General Steering Committee, an Advisory Panel, a Research Management Group and a Consumer and Community Reference Group (see Appendix D).

Cross-agency data linkage has enabled numerous important research projects utilising education data. Recently, researchers utilising linked cross-agency data through the DPP have investigated:

- The relationship between diet and educational outcomes;
- The impact of juvenile offending on educational outcomes in children with and without attention deficit hyperactivity disorder;
- Educational outcomes and trajectories for children in contact with child protection;
- The effects of out-of-home care on educational outcomes;
- Patterns of participation and factors predicting absence in academic testing;
- The effect of timing of risk factors on educational outcomes;
- The relationship between educational outcomes and mental health;
- The relationship between child and maternal chronic illness and developmental vulnerability at school entry;
- The relationship between parental mental illness and lower school readiness; and
- The effect of school absence on school performance in children with and without orofacial clefts.

While the DPP has been very successful in facilitating the infrastructure linkage of a number of non-health population data assets to the WADLS, there are a number of issues that have impacted the ability of researchers and government to access cross-agency linked data in a timely and efficient manner. These are discussed below.

The Data Linkage Branch has a limited capacity that prevents ready access to data by researchers and government. Current capacity issues have contributed to increasing delays in data delivery over the last 3-5 years, with some PhD researchers waiting up to two years to receive data. Long delays can potentially lead to researcher frustration, a waste of research funds, less useful data and analyses for evaluation of policies and practices, and much valuable research and evaluation not being done.

The data application process is extensive, and there are multiple unnecessary pathways required for approval. Moving forward, it is important for approval processes to be streamlined and based on a centralised approval process, and for data custodians to provide approval at just one stage of the application process. There may also be scope for single cross-agency ethics approvals in the future under a whole-of-government model.

Risk aversion has led to increasing restrictions in data availability, with limits imposed on the variables made available to researchers and important data items withheld. While it is important to manage risk, there is also a need to balance this to encourage the use of data in a timely fashion to improve services. A significant point to note is that in 35 years of data linkage in WA there has not been a single breach of privacy.

There is no privacy legislation applicable to WA State government agencies. The use and disclosure of confidential information is restricted by statutory duties of confidentiality and the common law duty of confidentiality. There is a need for enabling legislation, such as a Data Linkage Act/Privacy Act, balanced between privacy rights and data sharing, to support data custodians and enable

research for the public good. Any legislation should also ensure compatibility with Commonwealth principles so WA data can interface with data from the Commonwealth and other States.

There is also a need for improved knowledge management within agencies to ensure there are valid, accurate and complete data collections. Data should be underpinned by sound metadata, with data quality statements, operational databases, and data dictionaries.

Centre for Data Linkage

The Centre for Data Linkage (CDL) is hosted by the Curtin Health Innovation Research Institute (CHIRI) at Curtin University. It is responsible for enabling linkage between jurisdictional datasets, and between these datasets and research datasets for the purpose of health and health related research projects (Population Health Research Network, 2011). The CDL also has a large capacity for linkage, and could be used with existing State capabilities to manage demand and capacity issues. The CDL is an integral part of the Population Health Research Network (PHRN) and is the main data linkage facility for national projects run under the PHRN collaboration (Population Health Research Network, 2011).

COAG Reform Council

The experience of the Intergovernmental Agreement on Federal Financial Relations resulted in common objectives and outcomes (Nous, 2009). It did not always include reporting templates or guidance on the type of data to be collected or how it was to be reported. This resulted in the inability to compare progress across jurisdictions and establish a national picture – even where there was agreement across the Federation on both the framework and the need to collect data.

Data capture, processing and management

Is a fear of exposing program failure a serious impediment to data development and use? What can be done to overcome this?

Both the Telethon Kids and Institute and the Life Course Centre's submissions concur that fear of exposure of program failure is a serious impediment to data development and use.

The experience internationally with 'high stakes' data sounds a warning related to the use of data to reward those considered to be doing well. Some of our researchers have also experienced data owners or custodians requiring that some data not be collected or analysed in certain ways, and/or sections of reports and data not be released for unidentified reasons.

Technology

What are the main barriers to the greater adoption of technology (including mobile devices) to improve the quality and/or timeliness of data collection, processing and use?

The current reliance on paper records increases the risk of transcription errors and duplicate entries. Introducing an online school enrolment form would greatly assist in reducing these problems as well as reducing the administrative burden on schools. By designing the forms in such a way that non-entry of data is precluded, the completeness and accuracy of datasets would be greatly improved.

The Commission needs to recognise the challenges associated with accessing technology in rural and remote communities.

Not all rural and remote locations enjoy the level of access to the mobile network and internet that metropolitan areas expect. Some communities have no mobile network coverage and internet bandwidths may preclude the use of some software. Bandwidths can also vary at different times. In some locations IT service support may be many hours' drive away and very expensive. Funding available to independent, remote community schools is very limited. A national education evidence base needs to take these realities into account in its design.

Analytical and research capability

How effective have the different jurisdictional approaches to facilitating education research been in building research capacity?

The need for dedicated government funded research centres in early childhood education and development is supported in this submission. Currently, there is a significant lack of research capacity within the education sector, especially when compared to the health sector. Undergraduate teaching courses for example, do not enable teachers to understand how to interrogate evidence to determine its quality and relevance to their context and the education system has limited embedded analytic capability and financial support to enhance the research capabilities of teachers and other school staff.

Professor Jonathan Carapetis
Director, Telethon Kids Institute;
Centre for Child Health Research, The University of Western Australia

Appendix A

Framework	Guiding Principles	Outcomes	Performance indicators/Measures
ARACY Nest (National Action Plan for Child and Youth Wellbeing) (Australian Research Alliance for Children and Youth (ARACY), 2014, Australian Research Alliance on Children and Young People (ARACY), 2014) 0-24 years	A commitment to: <ul style="list-style-type: none"> • The child at the centre • Privileging Aboriginal and Torres Strait Islander knowledge • A long-term evidence informed approach • Prevention and early intervention • A life-stage approach • Systemic change using an outcomes approach. 	The strategic outcomes that underpin The Nest vision are six, broad, inter-related domains of child and youth wellbeing that research and evidence suggest are essential for children's current and future wellbeing: <ol style="list-style-type: none"> 1. Being loved and safe 2. Having material basics 3. Being healthy 4. Learning 5. Participating 6. Positive sense of culture and identity (which underpins all of the above) 	Measured by Australia being consistently placed in the top third of OECD countries for comparable indicators of child and youth wellbeing, with the target of 50% of indicators in the top third by 2025 (26% as at 2014). <ol style="list-style-type: none"> 1. Loved and safe <ul style="list-style-type: none"> • Positive, supportive family environment • Positive parenting practices • Positive, trusted peer relationships and communication • Community safety • Children not placed in care • Youth not in detention 2. Material basics <ul style="list-style-type: none"> • Material wellbeing • Income equality • Parental employment • Youth in employment/training/education • Internet access • Educational possessions • Housing amenity and stability

Continued on next page

Framework	Guiding Principles	Outcomes	Performance indicators/Measures
			<p>3. Healthy</p> <ul style="list-style-type: none"> • Healthy birthweight • Immunisation rates • Nutrition, activity and healthy weight • Healthy physical development • Dental health • Good mental health • Reduced injury deaths • Reductions in teenage pregnancies • Reduced substance use • Reduced youth violence <p>4. Learning</p> <ul style="list-style-type: none"> • Early childhood education participation • Reduced early childhood developmental vulnerability • Parental engagement in child learning • Performance in English, Maths and Science (at Year 4 and 15 years) • School retention rates • Youth participation in education <p>5. Participating</p> <ul style="list-style-type: none"> • Youth feeling able to have a say • Voting enrolment • Use and engagement of technology and social media • Involvement in organised activities • Membership of social, community, or civic groups <p>6. Positive sense of culture and identity</p> <ul style="list-style-type: none"> • Measures yet to be identified

Continued on next page

Framework	Guiding Principles	Outcomes	Performance indicators/Measures
			<p>The Nest sets a number of priority directions:</p> <p>Improving early childhood learning and development GOAL: Reduce percentage of children identified as developmentally vulnerable on the AEDI to 15% by 2020.</p> <p>Improving the educational performance of young Australians GOAL: Make Australia rank within the top 5 OECD countries for educational performance by 2025.</p> <p>Improving the physical health of young Australians GOAL: Make Australia rank within the top 5 OECD countries for physical health outcomes by 2025.</p> <p>Improving the social and emotional wellbeing of young Australians GOAL: Make Australia rank within the top 5 OECD countries on the UNICEF measures for social and emotional wellbeing by 2025</p> <p>Promoting the participation of young Australians GOAL: Develop and formalise national structures and frameworks for implementing and evaluating children and young people's participation.</p> <p>Reducing disadvantage arising from income disparity GOAL: Ensure Australia ranks as one of the top 5 OECD countries with the lowest percentage of children (0-15 yrs) in relative poverty* by 2025.</p> <p>* Children (0-15 years) in households with less than 15% median income</p>

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Framework	Guiding Principles	Outcomes	Performance indicators/Measures
<p>Striving for a better future for our kids and knowing whether we're achieving it: Establishing the foundations for a shared outcomes framework for 0-8 year olds (Centre for Social Impact, 2016)</p> <p><i>In progress</i></p>	TBC	<p>This project is part of the Opportunity Child initiative. It will provide a critical foundation for a shared outcomes framework for early childhood. It aims to identify key outcome areas for 0-8 year olds within an ecological framework; identify quality indicators that can be matched to outcome areas (using an evidence base); and provide a rationale and recommendations for outcomes and indicators that can be tested with key stakeholders and applied within communities.</p>	TBC

Appendix B (Data Linkage WA, 2016)

Data Linkage WA

Datasets linked via the WA Data Linkage System Infrastructure

This table lists the data sets approved as part of the Western Australian Data Linkage System (WADLS) infrastructure. Note:

- It excludes ad hoc data linkages that are carried out on a project-specific basis and comprise specific data sets that are not part of the dynamic WADLS.
- The linkage frequency (see 'Comments') is a guide only.
- The addition and maintenance of non-core linkage infrastructure to the WADLS is contingent upon sufficient funding for initial development and ongoing operational costs.

For further information, please contact the DLB Project Manager, Alexandra Godfrey at alexandra.godfrey@health.wa.gov.au or phone (08) 9222 2370.

Dataset Name & Description	Custodian/Contact	Variable List available	Date range available	Comments
"Core" Datasets				
Birth Registrations	Janine Alan (Custodian)	Yes. DLWA website	1974 – previous month	Linked monthly
Death Registrations	Tom Eitelhuber (Contact)	Yes. DLWA website	1969 - previous month	Linked monthly
WA Electoral Roll		Yes. DLWA website	1988 – previous quarter	Linked quarterly Only last 'current elector' record released
Hospital Morbidity Data System (HMDS)	Paul Stevens	Yes. DLWA website	1970 – 6 months ago	Linked monthly ~6 month lag on records being coded and entered into HMDS
Mental Health Information System (MHIS)	Jo Harman (Acting)	Yes. DLWA website	1966 - 6 months ago	Linked quarterly ~6 month lag on records, in line with HMDS
WA Cancer Registry	Tim Threlfall	Yes. DLWA website	1982 - previous month	Linked monthly
Midwives Notification System (MNS)	Maureen Hutchinson	Yes. DLWA website	1980 – June 2014	Linked monthly but a lag exists in data completeness
Emergency Department Data Collection (EDDC)	Andrew Puljic	Yes. DLWA website	2002 – previous month	Linked monthly
Other WA Health Datasets				
BreastScreen WA (BSWA)	Elizabeth Wylie (Custodian)	No.	1995 - 2013	No linkage schedule currently.

Dataset Name & Description	Custodian/Contact	Variable List available	Date range available	Comments
	Janette Tresham (Contact)	Contact Custodian		
Health and Wellbeing Surveillance System (HWSS)	Sarah Joyce	Yes. DLWA website	2002 – current	Linked quarterly.
Home and Community Care (HACC)	Rob Willday (Custodian) Lauren Melling (Contact)	Yes. Contact DLB Client Services	2004 - 2014	Linked annually.
Hospital Pharmacy Data AScribe iPharmacy	Richard Wojnar-Horton (Custodian) Karen Phillips (contact)	No. Contact Custodian	1999 - 2009 2009 - 2013	No linkage schedule currently.
Monitoring of Drugs of Dependence System (MODDS)	Neil Keen (Custodian) Susan Gontaszewski (Contact)	Yes. Contact DLB Client Services	1998 – 2013	Linked annually.
State Trauma Registries Royal Perth Hospital Sir Charles Gairdner Hospital Princess Margaret Hospital Fremantle Hospital Joondalup Hospital	Maxine Burrell Sandra Spensley Brennan Ta Jane Scurr Glynis Porter Amanda Foster	No. Contact Custodians	Aug 1994 – Dec 2014 Jan 1997 – July 2014 Aug 1998 – July 2014 Jan 1997 – Nov 2013	Linked annually.

Dataset Name & Description	Custodian/Contact	Variable List available	Date range available	Comments
Fiona Stanley Hospital			Jan 2010 – Nov 2013 Not yet linked.	
WA Notifiable Infectious Diseases Database (WANIDD)	Gary Dowse (Custodian) Carolien Giele (Contact)	Yes. Contact DLB Client Services	1990 – current	Linked annually.
WA Register of Developmental Anomalies (WARDA) - Birth Defects	Co-custodians: Hugh Dawkins Gareth Baynam	Yes. DLWA website	1980 – 2013	Linked annually. Applicants must submit separate lay summary to Custodian.
WA Register of Developmental Anomalies (WARDA) - Cerebral Palsy	Gareth Baynam (Contact Birth Defects) Linda Watson (Contact Cerebral Pals)	Yes. DLWA website	1956 – 2013	Linked annually. Applicants must submit separate lay summary to Custodian.
Other WA Government Datasets				
Department for Child Protection and Family Support	Kaija Pay (Contact)	Yes. Email contact for current list	1994 - 2013	Restricted to Developmental Pathways Projects.
Department of Corrective Services - Adult Justice		Yes. Contact DLB Client Services	1985 – 2013	Linked annually. Restricted to Developmental Pathways Projects. Applicants must also apply to the DoCS Research Evaluation Committee (REC).
Department of Corrective Services (DoCS) – Juvenile Justice		Yes. Contact DLB Client Services	1980 – 2013	
Department of the Attorney General (DotAG) – Courts Data	Monica Cass (Contact)	No. Email Contact for current list	2000 – 2012 For people born 1980 – 1997	Linked annually. Restricted to Developmental Pathways Projects. Applicants must also apply to the DotAG Research

Dataset Name & Description	Custodian/Contact	Variable List available	Date range available	Comments
			with a record in the court system 2000 - 2012	Application and Advisory Committee (RAAC). Variables to be discussed with the Department project by project.
Department of Education (DoE) – Attendance & Suspension	Alan Dodson	Yes. Contact DLB Client Services	2008 - 2012	Linked annually. Restricted to Developmental Pathways Projects. Applicants require approval from DoE to access data held by DoE.
Department of Transport (DoT) – Licensing Data	Christopher Davers	No. Contact Custodian	1985 - 2012	Applicants must receive approval to access data held by DoT.
Insurance Commission WA(ICWA) Injury Claims Data	Robert Marchesi	Yes. Contact DLB Client Services	1985 - 2010	Linked monthly. Applicants must receive approval from ICWA.
Other Datasets				
Australian Early Development Census (AEDC)	Rebecca Tadman	No. Email contact for list	2009, 2012	Census taken every three years & linked approximately 1-2 years after completion. See application process at http://www.aedidata.com.au/
Intellectual Disability: Exploring Answers Database (IDEA)	Helen Leonard (Custodian) Jenny Bourke (Contact)	Yes. Contact DLB Client Services	1953 - 2013	Linked annually.
Playgroups WA	David Zarb	No. Contact DLB Client Services	2006 - 2012	No linkage schedule currently. Restricted to Developmental Pathways Projects.
Silver Chain Nursing Association	Gill Lewin	No. Contact Custodian	2003 - 2013	Linked annually.
St John Ambulance	Co-custodians: Judith Finn Paul Bailey	Yes. Contact DLB Client Services	1980 - 2013	No linkage schedule currently. Requires approval from SJA Research Advisory Group.

Dataset Name & Description	Custodian/Contact	Variable List available	Date range available	Comments
	Belinda Thorne (Contact)			

Appendix C (McKenzie, 2016)

Senate Select Committee on Health Inquiry - Improving access to and linkage between health data sets held by Commonwealth entities

Presentation by Anne McKenzie, February 2nd 2016

Good afternoon

Since 2004 I have worked at The University of Western Australia's School of Population Health and the Telethon Kids Institute as the consumer advocate and now manage the Consumer and Community Involvement Program. My key role is to support researchers, consumers and community members to work together to make decisions about research priorities, policy and practice at these two organisations. We support 29 committees with membership of 186 consumers and community members – 14 of these committees are for linked data research projects.

In the past 12 years the Involvement Program has, amongst other activities held:

- 14 state and national training workshops for consumers and community members on basic research information including information about government held data collections and the linked data capability that has been developed across Australia
- 65 community forums on a wide range of research topics which have been attended by over 1420 consumers and community members - a third of these forums were about research linking state and/or commonwealth data sets.

I have also been an active consumer advocate for over 20 years. I am a senior consumer representative for Consumers Health Forum of Australia and former Chair of Health Consumers Council of WA. In both my professional and voluntary consumer advocacy work I have seen a definite shift in attitudes to linked data research amongst health consumers across the country – starting as one of concern about privacy issues and moving to one of overwhelming support for administrative data collections being used to conduct independent research that will impact on health policy and practice and ultimately make a difference to health outcomes for Australians. A consumer stated the following at a community forum in 2015: “a decade ago we were strongly opposed to it (linked data research), after 10 years of coming to understand exactly where the risks lie, and more importantly where they don't, we are now the strongest supporters of using data to conduct meaningful research”.

Today I would like to speak to you on behalf of the 80 consumers and community members who have or continue to serve on four high level committees at the School and the Institute during the past decade. Since 2007 these committees have become aware of important health research projects are that have been either held up or not completed because of ongoing delays and limited access to commonwealth and state health datasets. They have expressed disbelief, grave concerns and finally outrage that this situation has been allowed to continue over a long period of time. These delays have continued regardless of multiple meetings, letter writing and lobbying by researchers, academic organisations, state government agencies, consumers and community members.

I would like to share with you some specific points raised by consumers and community members at many meetings held at the School of Population Health and the Telethon Kids Institute since 2007:

- There is an expectation in the community that governments will meet their responsibilities to use the data to conduct independent health research.
- Not doing this is not only morally wrong it is also a gross waste of public money. This is particularly concerning when research that has been approved, funded and deemed ethically appropriate but cannot be undertaken because the data are not made available.
- When consumers and community members have raised concerns either in person to government agencies or through correspondence, so called 'privacy concerns' have been put forward as a key reason for the lack of access or long delays. Consumer and community members have an expectation that government agencies will have rigorous governance and access processes to deal with any potential privacy issues to enable the full use of the data.
- Important research questions are not being asked and answered because of access and delay issues surrounding the use of Commonwealth health data. We have become aware of a growing culture amongst researchers not undertaking research that requires access to Commonwealth data sets. Following is a direct quote made by a researcher in a grant application being submitted this year:

"We elected not to request MBS and PBS data from the Commonwealth as local and national jurisdictional sensitivities still persist with its provision at the population level. In addition, there is a real risk that we would not receive the data in time for analysis within the allotted study period". The funds are being requested for a 4-year study."

- The lack of transparency about the processes and guidelines used by data custodians to make decisions about who can access to Commonwealth data. Are community priorities for research considered?

In conclusion I would just like to reiterate that the numerous consumers and community members who have been served on committees in our Involvement Program, when they become aware of issues surrounding long delays and lack of access to health data holding back important research, are overwhelmingly disappointed and outraged that this wasteful situation is allowed to continue and that Commonwealth and state governments are not working together to maximise the use of the data they collect. I would like to finish with some direct quotes from consumers and community members put forward at a linked data forum held in WA in November 2014:

- "Who are these data custodians, who makes their rules – do they think they own the data?"
- "Government intrudes on just about every area of our life for reasons that aren't always clear' yet we have information that can be de-identified and used to help treatment or policy changes and yet it's put it in the too hard basket"
- "Why aren't governments facilitating more research to be done with information they already have"
- "I know the data are anonymised but I want you to remember that it's my story – it's about me, my life, my family. Researchers and governments should honour that by making information available about what the data are used for and what is found"

Thank you

Appendix D

Developmental Pathways in WA Children Project Governance

The Directors' General Steering Committee includes the Directors General from all participating agencies. The Committee directs policy based research and sets the research agenda. The members are responsible for deciding the priority areas for their agencies and directing researchers toward those key areas.

The Advisory Panel sits below the Directors' General Steering Committee and provides high level advice and expertise to the researchers. The Advisory Panel has members from each of the government departments as well as the Telethon Kids Institute.

The Research Management Group sits below the Advisory Panel and is kept informed of all scientific, research and management issues. This Group also has members from each of the government agencies, members from the Telethon Kids Institute, and all the researchers involved in the DPP.

Directors' General Steering Committee	
Professor Fiona Stanley (Chair) Patron Telethon Kids Institute	Mr Alistair Jones (Co-chair) Executive Director Department of Treasury
Professor Jonathan Carapetis Director Telethon Kids Institute	Dr Karl O'Callaghan Commissioner of Police WA Police
Dr Rebecca Glauert Program Manager, Developmental Pathways Project Telethon Kids Institute	Dr Ron Chalmers Director General Disability Services Commission WA
Ms Jennifer Mathews Director General Department of Local Government and Communities	Mr James McMahon Commissioner Department of Corrective Services
Ms Emma White Director General Department for Child Protection and Family Support	Mr Paul Whyte Acting Director General Department of Housing
Dr David Russell-Weisz Director General Department of Health	Mr Cliff Weeks Director General Department of Aboriginal Affairs
Mr Timothy Marney Commissioner Mental Health Commission	Dr Ruth Shean Director General Department of Training and Workforce Development
Ms Sharyn O'Neill Director General Department of Education	Ms Cheryl Gwilliam Director General Department of the Attorney General

Directors' General Steering Committee Terms of Reference

The purpose of the Steering Committee is to provide a forum for high-level strategic policy discussion and direction giving in relation to evidence and findings from the DPP. This includes:

- Application of research findings to support appropriate policy development and review across the public sector
- Identification of cross sector linkages in the application of research findings
- Providing strategic direction to the research work of the Advisory Panel
- Prioritising the work of the DPP to support appropriate policy development and discussion across the WA public sector
- Considering the application of WA's unique, cross-agency data linkage infrastructure to inform other evidence-based policy priorities
- Providing high-level evaluation and review of the application of any research findings to policy development
- Providing ongoing monitoring and reviews of WA's cross-agency data linkage capability.

Advisory Panel	
Professor Fiona Stanley (Chair) Patron Telethon Kids Institute	Dr Rebecca Glauert (Co-chair) Program Manager, Developmental Pathways Project Telethon Kids Institute
Ms Marilyn McKee Manager, K-10 Testing School Curriculum and Standards Authority	Ms Sue Kiely A/Director Performance and Reporting Child and Adolescent Health Service Department of Health WA
Ms Anne McKenzie Consumer & Community Participation Program Manager Telethon Kids Institute	Ms Alexandra Godfrey Project Manager, Client Services Data Linkage Branch Department of Health WA
Mr Kurt Sibma Assistant Director Department of Treasury	Mr Andrew Marshall Manager, Research and Analysis Department of the Attorney General
Mr Richard Matthews Quality & Performance Reporting Manager Disability Services Commission	Mr Stephen Jones Assistant Director, Business Intelligence & Reporting Department of Corrective Services
Dr Janine Alan Data Linkage Branch Program Manager Department of Health WA	Mr Anthony Kannis Executive Director WA Police
Mr Alan Dodson Director, Evaluation & Accountability Department of Education	Ms Sarah Mewett Manager Analytics and Market Intelligence Housing Authority
Ms Julie Dixon Director Policy - Family Support and Reporting Department for Child Protection and Family Support	Mr Ben Halton Director Intergovernmental Unit Department of Aboriginal Affairs
Mr Tony Satti Program Manager, Data Collection and Analysis, Performance Activity and Quality Division Department of Health WA	Professor Nicholas de Klerk Head, Bioinformatics and Data Services Telethon Kids Institute
Mr Michael Moltoni Director, Performance, Monitoring and Evaluation Mental Health Commission	

Advisory Panel Terms of Reference

- Participate in Biannual Strategic Planning Seminar
- Provide high level advice and expertise
- Represent partner organisations in decision making processes
- Communicate, liaise and advocate directly with organisational leaders in matters pertaining to the work program
- Ensure work program and outputs are consistent with agreements/Memorandums of Understanding (MoUs)
- Oversee privacy and confidential issues
- Provide advice on strategic media release issues.

Research Management Group	
Dr Rebecca Glauert (Chair) Program Manager, Developmental Pathways Project Telethon Kids Institute	Dr Helen Leonard Principal Research Fellow Telethon Kids Institute
Professor Nick de Klerk Head, Bioinformatics and Data Services Telethon Kids Institute	Ms Anne McKenzie Consumer & Community Participation Program Manager Telethon Kids Institute
Dr Melissa O'Donnell NHMRC Early Career Fellow Telethon Kids Institute	Mr Chris Dorrian Principal Information Analyst, Accountable Government Department of Aboriginal Affairs
Mr Bruce Miller WA Police	Ms Sarah Mewett Manager Analytics and Market Intelligence Housing Authority
Mr Michael Bosley-Smith Research and Evaluation Department of Local Government and Communities	Associate Professor Anna Ferrante Deputy Director of the Population Health Research Network (PHRN) Centre for Data Linkage Curtin University
Ms Kaija Pay Senior Information, Research and Evaluation Officer Information, Research and Evaluation Department for Child Protection and Family Support	Ms Jenny Offer Principal Consultant - Certification School Curriculum and Standards Authority
Dr Monica Cass Senior Evaluation and Research Officer Policy and Aboriginal Services Directorate Department of the Attorney General	Ms Alice Findlay Manager, Research and Evaluation Policy and Learning Department for Child Protection and Family Support
Ms Karen Forde Research Officer Project Management Office Child and Adolescent Health Service Department of Health WA	Dr Stephen Thorpe A/Principal Consultant Behaviour K-12 Coordination Department of Education
Ms Vikki Miroseovich Acting Manager Hospital Morbidity Data Collection Hospital Morbidity Department of Health WA	Mr Tom Eitelhuber Manager, Data Linkage Systems Data Linkage Unit Department of Health WA
Mr Andrew Puljic Manager, Emergency Department Data Collection Department of Health WA	Mr Ed Wilson Senior Planning & Performance Analyst Disability Services Commission
Dr Gareth Baynam Manager, Western Australian Registry of Developmental Anomalies Department of Health WA	Professor Cate Taylor Research Professor and Principal Research Fellow Telethon Kids Institute
Ms Alexandra Godfrey Project Manager, Client Services Data Linkage Branch Department of Health WA	Ms Jo Harman Manager, Mental Health Information System Department of Health WA
Dr Amanda Harrison A/Manager, Research and Evaluation Performance, Monitoring and Evaluation Mental Health Commission	Professor Steve Zubrick Senior Principal Research Fellow Telethon Kids Institute

Ms Maureen Hutchinson Manager, Maternal and Child Health Unit Midwives Notifications, Abortion Notifications and Reproductive Technology Registers Department of Health WA	Dr Natasha Nassar Principal Research Fellow and NHMRC Career Development Fellow Clinical and Population Perinatal Health Research Kolling Institute of Medical Research
Ms Samantha Kelly Senior Planning Analyst, Knowledge & Information Technology Department of Corrective Services	Post-graduate students

Research Management Group Terms of Reference

- Meet 6-8 times per year
- Ensure participants are kept informed of all scientific, research and management issues
- Develop and monitor strategic direction for research program
- Oversee student supervision requirements
- Provide mentoring of people and research themes
- Ensure integrity of scientific direction and context of research including ethics and privacy considerations
- Ensure Industry Partners are being served by the relevant projects
- Review requests for access to data linked as a result of the ARC Linkage Grant through the Submissions Review Group
- Maintain a register of research projects that have used data linked as a result of the ARC Linkage Grant
- Ensure researchers submit progress reports
- Contribute to preparation of annual report
- Manage and be responsible for financial and expenditure operations.

References

- ADAMSON, P. 2008. The child care transition: A league table of early childhood education and care in economically advanced countries. Report Card 8. Florence: UNICEF, Innocenti Research Centre.
- AUSTRALIAN INSTITUTE OF HEALTH AND WELFARE (AIHW) 2007. Young Australians: their health and wellbeing. *In*: AIHW (ed.). Canberra: Commonwealth of Australia.
- AUSTRALIAN RESEARCH ALLIANCE FOR CHILDREN AND YOUTH (ARACY) 2014. The Nest action agenda. Improving the wellbeing of Australia's children and youth while growing our GDP by over 7%. 2nd ed. Canberra: ARACY.
- AUSTRALIAN RESEARCH ALLIANCE ON CHILDREN AND YOUNG PEOPLE (ARACY) 2014. *The Nest Action Agenda: Technical Document*. Canberra: ARACY.
- BELSKY, J., VANDELL, D. L., BURCHINAL, M., CLARKE-STEWART, K. A., MCCARTNEY, K. & OWEN, M. T. 2007. Are There Long-Term Effects of Early Child Care? *Child development*, 78, 681-701.
- BRONFENBRENNER, U. 1979. Toward an experimental ecology of human development. *American psychologist*, 32, 513.
- BURGER, K. 2010. How does early childhood care and education affect cognitive development? An international review of the effects of early interventions for children from different social backgrounds. *Early Childhood Research Quarterly*, 25, 140-165.
- CENTER ON THE DEVELOPING CHILD 2007. A Science-based Framework for Early Childhood Policy: Using Evidence to Improve Outcomes in Learning, Behavior, and Health for Vulnerable Children. Cambridge, Massachusetts: Center on the Developing Child, Harvard University.
- CENTER ON THE DEVELOPING CHILD 2010. The Foundations of Lifelong Health. *In*: CENTRE ON THE DEVELOPING CHILD, H. U. (ed.). Cambridge, Massachusetts: Centre on the Developing Child, Harvard University.
- CENTRE FOR SOCIAL IMPACT. 2016. *Striving for a Better Future for our Kids and Knowing Whether We're Achieving It: Establishing the foundations for a shared outcomes framework for 0-8 year olds*. [Online]. Available: <http://www.csi.edu.au/research/project/striving-better-future-our-kids-and-knowing-whether-were-achieving-it-establishing-foundations-shared-outcomes-framework-0-8-year-olds/> [Accessed 10th May 2016].
- D'ARCY, C., HOLMAN, J., BASS, A. J., ROSMAN, D. L., SMITH, M. B., SEMMENS, J. B., GLASSON, E. J., BROOK, E. L., TRUTWEIN, B., ROUSE, I. L., WATSON, C. R., KLERK, N. H. D. & STANLEY, F. J. 2008. A decade of data linkage in Western Australia: strategic design, applications and benefits of the WA data linkage system. *Australian Health Review*, 32, 766-777.
- DATA LINKAGE WA. 2016. *Data Linkage Western Australia. Enabling health and medical research in Western Australia* [Online]. Government of Western Australia. Department of Health. Available: <http://www.datalinkage-wa.org.au/> [Accessed 10th May 2016].
- DEPARTMENT OF EDUCATION AND TRAINING 2016. Australian Early Development Census – National Report 2015. Canberra: Australian Government Department of Education and Training.
- DEPARTMENT OF SOCIAL SERVICES. 2016a. *Data Exchange* [Online]. Available: <https://dex.dss.gov.au/> [Accessed 10th May 2016].
- DEPARTMENT OF SOCIAL SERVICES. 2016b. *DSS List of Registered CCMS software 23 March 2016* [Online]. Available: https://docs.education.gov.au/system/files/doc/other/list_of_registered_ccms_software_23_march2016.pdf [Accessed 9th May 2016].
- EMERSON, L., FEAR, J., FOX, S. & SANDERS, E. 2012. Parental engagement in learning and schooling: Lessons from research. A report by the Australian Research Alliance for Children & Youth (ARACY) for the Family-School and Community Partnerships Bureau. Canberra: ARACY.
- GOSS, P., AND CHISHOLM, C., 2016. Widening gaps: what NAPLAN tells us about student progress. Technical Report. Carlton: Grattan Institute.
- GOSS, P., SONNEMANN, J., CHISHOLM, C. & NELSON, L. 2016. Widening gaps: what NAPLAN tells us about student progress. Carlton: Grattan Institute.

- HANCOCK, K. J., LAWRENCE, D., MITROU, F., ZARB, D., BERTHELSEN, D., NICHOLSON, J. M. & ZUBRICK, S. R. 2012. The association between playgroup participation, learning competence and social-emotional wellbeing for children aged 4-5 years in Australia. *Australasian Journal of Early Childhood*, 37, 72-81.
- HANCOCK, K. J., MITROU, F., POVEY, J., CAMPBELL, A. & ZUBRICK, S. R. 2016. Three-Generation Education Patterns among Grandparents, Parents and Grandchildren: Evidence of Grandparent Effects from Australia. *LCC Working Paper 2016*, 08.
- HARRISON, L., SUMSION, J., PRESS, F., WONG, S., FORDHAM, L. & GOODFELLOW, J. 2011. A shared early childhood development research agenda: Key research gaps 2010-2015. Canberra: Research Institute for Professional Practice, Learning and Education (RIPPLE), Charles Sturt University and ARACY.
- HARRISON, L. J., UNGERER, J., SMITH, G. J., ZUBRICK, S. R., WISE, S., PRESS, F. & WANIGANAYAKE, M. 2010. Child care and early education in Australia - the longitudinal study of Australian children. In: DEPARTMENT OF FAMILIES, H., COMMUNITY SERVICES AND INDIGENOUS AFFAIRS (ed.). Canberra: Commonwealth of Australia.
- HECKMAN, J. J. 2006. Skill formation and the economics of investing in disadvantaged children. *Science*, 312, 1900-1902.
- JENSON, J. M. & FRASER, M. W. 2011. *Social policy for children and families: A risk and resilience perspective*, London, Sage.
- KIERNAN, K. E. & MENSAH, F. K. 2011. Poverty, family resources and children's early educational attainment: the mediating role of parenting. *British Educational Research Journal*, 37, 317-336.
- MCCAIN, M. N., MUSTARD, J. F. & SHANKER, S. 2007. *Early years study 2: Putting science into action.*, Toronto, Council for Early Child Development.
- MCKENZIE, A. 2016. Improving access to and linkage between health data sets held by Commonwealth entities. *Senate Select Committee on Health Inquiry*. Canberra: Commonwealth of Australia.
- NOUS GROUP 2014. Perspectives on the use of performance frameworks in the Australian federation. Research commissioned by the COAG Reform Council. Perth.
- PHILLIPS, D. A. & SHONKOFF, J. P. 2000. *From Neurons to Neighborhoods: The Science of Early Childhood Development*, Washington, DC, National Academies Press.
- POPULATION HEALTH RESEARCH NETWORK. 2011. *Centre for Data Linkage* [Online]. Available: <http://www.phrn.org.au/centre-for-data-linkage/> [Accessed 11 May 2016].
- ROYAL AUSTRALIAN COLLEGE OF PHYSICIANS 2006. Health of Children in "Out-of-Home" Care. Paediatric Policy. Sydney: Royal Australian College of Physicians.
- SILBURN, S. R., NUTTON, G., ARNEY, F. & MOSS, B. 2011. The First 5 Years: Starting Early. Topical paper commissioned for the public consultations on the Northern Territory Early Childhood Plan. In: GOVERNMENT, N. T. (ed.). Darwin: Northern Territory Government.
- STANLEY, F., GLAUERT, R., MCKENZIE, A. & O'DONNELL, M. 2011. Can Joined-Up Data Lead to Joined-Up Thinking? The Western Australian Developmental Pathways Project. *Healthcare Policy*, 6, 63-73.