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EVALUATION OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM

Running title: Evaluation of the IDEA system

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ABSTRACT

Objectives: Our overall aim was to evaluate the Western Australian 'Intellectual Disability Exploring Answers' (IDEA) surveillance system. The primary objective was to evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the system.

Method: The IDEA system was evaluated using process observation, interviews and secondary data analysis of system attributes: usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability. 2001 U.S. Centers for Disease Control and Prevention guidelines were used.

Results: We found that the IDEA system was flexible, acceptable, representative, timely and stable. We compared individuals from the IDEA system (n=10593) to those with cerebral palsy and ID (n=582) from another surveillance system. Of the 582 with cerebral palsy and ID, 501 (86.1%) were in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. There were little differences in cases that were not identified in the IDEA system between Indigenous status, sex and place of residence.

Conclusions: The strengths of the IDEA system include having a high data quality resource contributing to national and international data on ID, strong government support and a dedicated management team. Output from studies linking to IDEA data have had major contributions to the international literature about ID. However, limited resources have prevented it from realising its full potential in relation to translational activities. The IDEA system is a valuable resource to address the needs of people living with ID.

Strengths and limitations of this study

- This is one of the few surveillance systems internationally that collects ongoing data on people living with an ID. Evaluating this unique surveillance system ensures that it remains relevant in the face of a domestic policy changes and continues to be able to contributes to the international literature on ID.
- The methods used are highly acceptable for evaluating surveillance systems.
- We were unable to compare the system to the true population due to a lack of primary data.

INTRODUCTION

People living with an intellectual disability (ID) have impaired thought processes, learning, communication, and remembering, which contribute to their overall intelligence including cognition, and language and may affect motor and social abilities. As a result, people with IDs are more likely to suffer from maltreatment as children,[1] have increased co-morbidities,[2] mental health diagnoses[3] and often experience stigmatisation and discrimination resulting in poor access to health services[4] compared to their counterparts who do not have ID. In addition, with advances in health care, many people with ID now have elderly carers or will outlive their carers. Additional government input for care services previously managed by families will be needed in the years to come.[5]

Internationally there are few dedicated public health surveillance systems for ID. Many rely on data from existing state and national surveys, administrative datasets, registries or integrated data systems.[6-8] In Western Australia (WA), the 'Intellectual Disability Exploring Answers' (IDEA) database is a population-based linked data surveillance system which is internationally recognised for its collection of prevalence and incidence data for ID.[9] The IDEA system originated from a dataset of individuals with ID receiving support from the WA government, was established in 1953 and maintained by successive state governments performing this role. In 2002, the IDEA system was moved to the Telethon Kids Institute (TKI, WA) to become a permanent population-based data linkage surveillance system. The original objective of the surveillance system was to provide high-quality, complete and population based information on ID in WA. It was anticipated that this information might be used for the following purposes: monitoring trends and investigating changes in the prevalence of ID, overall and in various subgroups; providing an infrastructure for population-based epidemiological and genetic research into the causes and prevention of ID; providing an infrastructure for research into the health status and service needs of children and adults with ID; allowing the identification of population based subgroups with specific characteristics who might benefit from new scientific advances; evaluating screening programs for prevention of ID; facilitating planning and providing infrastructure for the evaluation of early intervention and therapy programs; and increasing community and professional knowledge about ID.[10]

With the recent introduction of the Australian National Disability Insurance Scheme (NDIS), the future of the IDEA surveillance system has become unclear. It is still not known whether government will continue to undertake assessments for ID, the information needed to categorise cases in the IDEA system.[11] Information on the current strengths and limitations of the IDEA surveillance system could help stakeholders and data custodians better understand how the system can evolve in light of current policy initiatives. Therefore, an evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objective was to systematically and objectively evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

METHODS

Design

This evaluation is based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems.[12] We assessed the following system attributes: usefulness (how important is the collection of ID; does it respond to prevention, early detection and evaluation of programs; or improve public health knowledge), simplicity (ease of understanding data processes), flexibility (ability of the system to adapt to changing needs), data quality (is the data complete), acceptability (the willingness of providers to participate in IDEA system processes), representativeness (is the data generalisable to the wider population), timeliness (speed of which data is provided at all stages), and stability (whether resourcing is sufficient). We did not aim to calculate positive predictive value and sensitivity due to lack of primary data to assess these attributes.

Study setting

Case ascertainment and eligibility

Cases are ascertained from the Disability Services Commission (DSC, now Department of Communities) through referrals to assess individuals for eligibility to access disability services. For the Department of Education cases are school aged children who are identified as potentially needing additional teaching support in relation to intellectual functioning and who have been assessed to determine the level of educational support required. Supplement 1 provides case eligibility for both DSC and Department of Education.

Eligibility for IDEA has been extended to children < 6 years old who are considered 'vulnerable' by the DSC when a developmental assessment indicates a likelihood of ID although they are too young to have a formal IQ assessment. These children are included in the database but are reconsidered if assessments become available at school age. This represents only approximately 2% of cases (estimated for birth years 1990–2001).[9] Children identified through the Department of Education were accepted as having an ID unless there is conflicting evidence from DSC.

Case definition

A confirmed case from the DSC is i) an individual with a full IQ<70; ii) evidence of developmental delay at <18 years of age (where evidence is not available but there is no obvious cause for the ID after 18 years of age, it is accepted that the delay was probably present during childhood and the case will be eligible); or iii) where there is no IQ test score available but the child has a known biomedical cause of ID, such as Down syndrome.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was 'mild or moderate' or severe. Subsequent to 2005 and in the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.[9] In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit AAMR system to assign the most appropriate cause of ID to cases[13] which can be later grouped into broader categories.

Management of IDEA system

Currently there is funding provided by the DSC for personnel equivalent to 0.5 FTE and operating costs. Personnel costs cover liaising with departments for data, updating data within the IDEA system, supporting and completing epidemiological studies on ID and responding to requests for data. Operating costs need to cover future fees for data linkage by Department of Health WA. Funds have also provided some support for traditional research outputs such as conference fees and publication costs. However, there has been limited support for work related travel, communication and engagement activities, which have been covered from other sources including a philanthropic donation in 2013. In addition, there is a volunteer community advisory group which consists of researchers, advocates for ID, policy makers and the IDEA system data custodian. The aim of the advisory group is to review and approve projects applying for the use of ID data in their study and to provide support where applicable. Although the advisory committee originally met annually in person, since 2011 communication between members has primarily been through email.

Patient and public involvement

Patient and public involvement were not completed for the study design or the development of outcome measures. A member of the public and an advocacy organisation for intellectual disability were recruited and provided their views on the IDEA system. The results will be disseminated through traditional journal publication, conference presentation and a lay summary, which will be sent to all individuals who participated in the project. We have acknowledged the time stakeholders spent in participating in the study.

Data collection

For privacy and confidentiality reasons there is a limited number of data variables that are collected as part of the IDEA system (Supplement 2). As a population-based data linkage surveillance system these data need to be linked to other WA administrative data collections.

The process of obtaining data for the IDEA system involves data contributions from two WA government departments, the DSC and the Department of Education. Figure 1 provides a flow diagram outlining the process from case ascertainment to finalising the IDEA system updates. Identifiable data on individuals with probable and suspected ID are provided to the Data Linkage Branch, Department of Health WA. These data are de-identified and only linkable through unique codes called root numbers, which are then provided back to the IDEA custodian and to the respective departments. Both departments then provide the IDEA management team with their de-identified datasets and data variables. This process is undertaken to safeguard privacy and confidentiality at all stages and takes approximately nine months to occur. Once the data are received by the IDEA team duplicates are combined into one record, new records are assessed for eligibility and the system updated (Figure 1). This latter process takes approximately four months to complete. Updates from DSC and the Education Department were initially undertaken every two years. However, there was four years between the last two updates (in 2013 and 2017). This delay was associated with the process of IDEA being converted to an Infrastructure Project.

Data analysis

To evaluate the IDEA surveillance system we took a three-pronged approach including process observation, in-depth interviews and secondary data analysis. Interviewees included representatives from the three WA government departments involved in the IDEA system, health service providers, community representatives and researchers using a 20-item semi-structured questionnaire. The aim of the interview was to discuss the usefulness, simplicity, flexibility, acceptability, sensitivity, timeliness, data quality, representativeness, and stability of the IDEA system through assessing and understanding responses of stakeholders. The questionnaire was administered face-to-face, took between 30-60 minutes and was recorded with participant's consent for further analysis. Some interviewees were not able to answer all questions depending on their level of involvement with the IDEA system. Thematic analysis according to the system attributes was completed.

Secondary data analysis was used to assess the data quality through determining the completeness of data. Cross-checking of individuals born between 1983—2014 from the mandatory WA Registry of Developmental Anomalies-Cerebral Palsy database (WARDA-CP) who have ID to the IDEA system was undertaken. ID for the WARDA-CP database is ascertained through medical records and is updated when a child is 5 years old. If there is no record of ID, the child's medical record will be checked again once they have started school. All confirmed cases from the IDEA system from 1983-2014 were included. Children from the WARDA-CP database were included in the analysis if they had a mild impairment (IQ or development quotient (DQ) 50-69), moderate impairment (IQ/DQ 35-49) or severe impairment (IQ/DQ <35). Cross-tabulations were completed to determine the number of children from the WARDA-CP database that were not identified in the IDEA system. If there was a discrepancy between databases further investigation to determine reasons for missing cases was completed.

Ethics approval

This study was approved by the Department of Health Western Australia Human Research Ethics Committee (2014/24), The University of Western Australia (RA/4/20/4168) and The Australian

National University (2017/567). Written consent was provided and all data collected was anonymous.

RESULTS

Characteristics

Eleven interviews were completed. Three individuals were solely involved in reporting, analysing and/or interpreting of ID surveillance data. Two contributed to the data either directly or in an advisory capacity. Six were involved in both of these roles. Interviewees had been involved with the IDEA system for 3-17 years and many of them contributed to the system in a number of different areas (Table 1). Other roles that were identified included administrative support, reporting, communication and translation.

Usefulness

Data on reasons for the importance of identifying and collecting ID data included:

- identifying prevalence and trends in ID
- using data for prevention of ID and to understand causes of ID, and management of care services
- identifying subgroups such as co-morbidity with mental illness, or child neglect for which ID is a very strong risk factor
- measuring and evaluating life outcomes for people with ID by being able to identify them as they move through the service system
- informing policy and practice particularly from a systems perspective for planning and resource allocation particularly as people with ID are the largest single cohort of individuals receiving support through all disability services.

Concern about the stigma associated with identifying people as having an ID was expressed although services, funding and resource allocation decisions are made as a result of these processes. Ensuring appropriate identification was considered an important part of the data collection process.

Interviewees thought the IDEA surveillance system had either met or partially met the overall aim of the IDEA system; to provide high-quality, complete and population based information on ID in WA. The IDEA surveillance system was considered to be an infrastructure which had provided a substantial amount of data to assess trends in the prevalence of ID, investigate health service use for people with ID, evaluate risks associated with having an ID and health and social determinants of ID. However, a major drawback in 2010 was the loss to the database of any information from the Western Australian Midwives database which provides an individual's basic birth data (born WA, race, birthweight etc.). As a result, other than through separate ethically approved data linkage projects, many of which have been undertaken, it is now difficult to provide many routine statistics. The system was also considered to be missing sub-groups of individuals such as the small number of people attending Catholic or independent schools for children born since 1992, individuals who were not receiving services from DSC or those not using the state education system. Additional data variables such as genetic information related to an individual's ID, co-morbidities, and in particular functional capacity, were commonly cited among interviewees as important information for IDEA. Interviewees agreed that evaluations of screening programs for prevention, early intervention or therapy programs for ID, or genetic research into the causes and prevention of ID had not been possible because of lack of availability of data or, if available, the presence of ethical and other constraints to its linkage. Lastly, it was acknowledged that although professional knowledge had increased about ID it was not known what impact this may have had on community awareness.

All interviewees had either used or read about the IDEA data in journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government reports, newsletters, minister reports, book chapters and conferences. There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data. Importantly, IDEA data have been widely used, cited and published in international literature including in international estimates of years lived with disabilities (2010).[14] However, there was unanimous agreement that there needs to be more publications, particularly consumer and policy-driven, as well as regular biannual reports. Although there had been direct engagement with the DSC Director General through meetings every 3 months in 2013 facilitated with philanthropic funding to provide information on outcomes, it was considered by many interviewees that there had been little in the way of communicating results to the community and advocacy organisations. It was suggested knowing this information could be beneficial for community groups to advocate with and for families and individuals with ID.

Simplicity

There were conflicting responses when asked about the simplicity of the system. Respondents discussed the process for collecting data for the IDEA surveillance system inconsistently as simple; timely; complex; or taking too long (Figure 1). However, ultimately the process is largely based on safeguarding privacy therefore the nine months it takes for the IDEA team to receive data was deemed by those who have worked with and in the Department of Health to be in line with current data linkage processes. The four months for integrating data received by government departments into the IDEA system was considered reasonable especially as there is only one person working 0.5 full time equivalent (FTE). The process of providing ID data for research projects was also perceived as appropriate and completed in a timely manner (Figure 2).

Flexibility

The IDEA system was relatively flexible to changes in personnel and case definitions. Personnel and process changes have occurred at all stages within the data process, with the exception of the TKI team. The TKI team has largely remained the same since the inception of the system in 2002. As a result the process of data linkage and extraction from the larger dataset received from Department of Health to the TKI team has not been documented to date. Although having a consistent team has created a system that is flexible and stable, as part of good practice and sustainability, developing formalised documented processes would be valuable. Case definitions have also varied with changes in how the Department of Education have recorded ID. These changes have been recorded and the system adapted accordingly for data integrity.

Data quality

There was universal agreement that the system was not complete for ID in WA with people attending Catholic or independent schools and individuals who were not receiving services from DSC likely to be missing from the system. In addition since mid-2014, individuals living in the Perth Hills region who were part of the NDIS pilot location had their data collected by the Australian Commonwealth government rather than the DSC WA.[15] Therefore there will be no data available on newly registered individuals with ID from this location at the next IDEA update.

Data quality is the responsibility of the two departments that assess individuals for ID. Each department has their own assessments for ID, reasons for collecting ID and ways in which the information is used. Ensuring data quality across organisations and that individuals with ID are correctly identified was seen as important for all people involved in collecting and using data.

We also assessed the completeness for individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, from the mandatory reporting surveillance system WARDA-

CP. Overall there were 10593 cases of ID in the IDEA system. 582 individuals were identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. Potential reasons for the discrepancies between the two sources were children who had died prior to school entry may not be identified in IDEA (n=8) and that WARDA may be including cases with probable or borderline ID who would not be eligible for IDEA. There were little differences in Indigenous status, sex and place of residence for cases not identified in the IDEA system (Table 2).

Acceptability

There are four organisations (Telethon Kids Institute, Department of Health WA, DSC, Department of Education) within WA that voluntarily participate in the IDEA surveillance system. Unlike other surveillance systems there are no mandatory requirements for case notification and therefore no onus on clinicians and other public health practitioners to participate. The two departments which supply data for the IDEA system do so voluntarily and deem the collection of data to be important. Memoranda of understanding have been signed by DSC and Education with the Department of Health for the release of data. In addition, there is an agreement between Telethon Kids Institute and Department of Education outlining the provision of education data to IDEA and a Grant Agreement between Telethon Kids Institute and DSC.

Representativeness

ID data within the IDEA surveillance system is dependent on individuals being referred (by clinicians, psychologists, allied health, teachers or parents) for services and/or being identified through the public education system. Since the IDEA system does not have mandatory notifications, it is not surprising that there are certain subgroups of individuals who may not be represented. Despite this, there is no other equivalent system elsewhere in Australia and these data have been used as a key data source for ID national estimates.[16] As a result the epidemiology findings are considered generalisable to the larger Australian population.

Timeliness

Overall the timeliness of the data was considered to be appropriate including the two year period between data extractions. The initial nine months for the data linkage process has previously been delayed through new staff having to extract the data from the two departments, resource limitations and priority delays within the departments. These barriers have resulted in delays at all stages of the nine month data extraction. It was also discussed that some of these time delays were the result of ensuring confidentiality, however, this is an important component of the system. Alternatively, it was mentioned that if individuals, organisations and policymakers valued the data then more frequent data extractions could occur.

Stability

Despite being a non-mandatory surveillance system, data has been regularly provided by departments and there has been ongoing funding negotiated. The funding provided has allowed for a 0.5 FTE position which supports personnel and operating costs. However, in-kind support from the TKI Disability team has also supported these activities and the day to day administrative tasks. The limited funding for the database has also restricted the amount of work that can be achieved within the IDEA system. Additional activities could include engaging with stakeholders, translation and communication of findings, use of IDEA data for supporting policy decisions and priority setting. It was estimated by those working directly with the system that 1.5FTE would be enough to complete the technical requirements of the IDEA surveillance system and be able to complete the additional tasks outlined.

DISCUSSION

The IDEA system is the only Australian population-based ID surveillance system and one of few internationally.[17-19] Since 2002, the IDEA system has been successfully funded and maintained by long-term collaborations with two WA departments. This has provided an infrastructure to understand prevalence rates and trends over time for ID, inform resource allocation, identify those at risk of negligence or other adverse events, identify risk and protective factors associated with ID and inform larger international studies on the global burden of disability.[1 14 20-23] Overall, the IDEA system was considered to be flexible, simple, acceptable, representative, timely and stable. However, components within these attributes such as insufficient engagement with stakeholders and community, lack of opportunities for translation and ensuring there is a workforce to deliver these initiatives could be improved.

Due to the IDEA system's data linkage capabilities, data from health, justice and child protection can be linked to determine important and complex associations both cross-sectionally and longitudinally for people living with intellectual disabilities. These data continue to provide important policy and program relevant implications and findings (Box 1). For example, the use of high quality administrative data has been used internationally to show the increased mortality rates due to potentially preventable conditions for people living with an ID compared to those without ID.[24 25] Using the IDEA system it has also been demonstrated that this issue exists and needs to be addressed in WA.[26] It has also highlighted the prevalence ID in WA has risen over the last 10 years from 14.3/1000 (births 1983-1992) to 17.0/1000 (births 1983-2005), representing an overall increase in prevalence of 19% from 1999 to 2010.[20] The use of high quality data is fundamental in dealing with the challenging health and social issues of people living with IDs, with the IDEA system addressing this need.

Many participants thought that sub-groups were missing within the IDEA system, however, this is likely to be a very small percentage of the population. Case ascertainment using two resources is high with previous research showing that between 1983-2003 only 50% of cases were ascertained through the DSC Services, with the remaining 50% from the Department of Education.[27] In addition, when considering the quality and quantity of services provided, as seen in WA, using administrative data sources results in high ascertainment of cases and therefore sound reporting of prevalence rates.[28] When comparing whether the WARDA-CP system had any additional cases not in the IDEA system there was a small percentage of cases missing. This equated to <1% of total cases in the IDEA system and reflects the high quality data source. The IDEA system provides coverage of ID considerably superior to that from other administrative datasets such as the WA Hospital Morbidity Data System.[29] Overall, the completeness of the IDEA system was high when compared to potential missing population data.

A major concern and impetus for completing this evaluation is the roll-out of the NDIS. Pilot trials have been completed nationwide for the NDIS with individual states currently determining the finer details of how the scheme will work. A common perception of the scheme is that not all individuals will need to be assessed for their disability, particularly ID, if they clearly meet the eligibility requirements. Although the collection of data may still occur at some level, it is possible that as a result of these changes ascertainment of ID will no longer occur through DSC (now Department of Communities). Although it is difficult to determine how this situation can be resolved for the IDEA system, the community advisory group has substantial clinical, policy and research experience to determine how this could occur. It is recommended that the advisory group start discussing and planning these changes in the near future. The development of a mechanism to ascertain cases through the NDIS remains a pressing issue.

The IDEA surveillance system has provided important clinical data on the health and social needs of people living with ID. Despite this there are a number of areas that the IDEA team could undertake to strengthen the system. Based on this evaluation we recommend the following:

1. Discussion and engagement with the IDEA advisory group on how ID could be collected in the future given the changes in data ownership to the Australian Government.
2. The IDEA team has been involved in the system since its initiation in 2002. As a result there have been few protocols developed for how data are linked, extracted and maintained. It is recommended that internal protocols are developed for future personnel working on the system. An additional 1FTE is also recommended to support additional activities proposed in these recommendations.
3. Active engagement with community and relevant stakeholders including disability organisations, policy makers, researchers and service organisations is sorely needed to promote awareness of current research and to determine priority setting for future research. This can be achieved through the development of communication and translation strategies as well as priority setting workshops.
4. Currently the IDEA team uses the Heber classification for the level of disability. This is an outdated system with other classification systems more up to date with current practice. Determining whether there are other classification systems that could be used and if the data could be moved to this system would be beneficial.
5. An additional variable for functional ability was considered to be important for informing current practice. Enhanced surveillance on a sub-group of individuals could be considered. To determine whether these data are important and if so what data would be included should occur in consultation with stakeholders.
6. The community advisory group should consider meeting annually again. This increased level of active engagement and strategic planning could influence the current activities of IDEA and inform future directions. Leadership is needed and the community advisory group are well placed to take on this role.

CONCLUSION

The IDEA surveillance system provides crucial data about people living with ID. However, there remains significant challenges in the future of the IDEA system given recent funding and service delivery changes within Australia. Changes to engagement with the community and stakeholders could play an essential role in the sustainability of the IDEA system through advocacy for its continuation. Enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families. The IDEA surveillance system is one of the few international ongoing data collections of ID. Discontinuing data collection and evaluation for this vulnerable population would be a disservice to society. Implementation of these recommendations will provide ways for the IDEA system to remain a successful source of important data for people living in with an ID.

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AUTHOR CONTRIBUTIONS

Conceived and designed the experiments: NS, JB, HL, AR. Performed the experiments: NS, JB. Analysed the data: NS. Contributed reagents/materials/analysis tools: NS, JB, HL, DM. Wrote and provided intellectual input into the paper: NS JB, HL, AR, KE, DM. All authors approved the final version. All authors are accountable for all aspects of the paper.

COMPETING INTERESTS

Author JB is employed to work on the IDEA system. Author HL is the data custodian of the IDEA system.

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DATA SHARING STATEMENT

Data are available through ethical approval from the relevant ethics committees in collaboration with the authors.

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Table 1: Roles identified by interviewees within the IDEA surveillance system

Characteristics	Numbers (%)*
Analysing data	8 (73%)
Reporting data	8 (73%)
Interpreting data	9 (82%)
Maintenance of data	5 (45%)
Data quality	7 (64%)
Committee member	4 (36%)
Data entry	3 (27%)
Data linkage	3 (27%)
Data extraction	3 (27%)
Management of data	6 (55%)
Advocacy	5 (45%)

*The are multiple counts

Table 2: Comparison of IDEA and WARDA-CP surveillance system data, 1982-2014

Variable	Total in WARDA-CP (n) %	Not in IDEA system (n) %	In both surveillance systems n (%)
Total	582	81 (13.9%)	501 (86.1%)
Alive	470 (80.8%)	69 (85.2%)	401 (80.0%)
Deceased	112 (19.2%)	12 (14.8%)	100 (20.0 %)
Indigenous status			
Indigenous	80 (13.7%)	15 (18.5%)	65 (13.0%)
Non-Indigenous	502 (86.3%)	66 (81.5%)	436 (87.0%)
Sex			
Male	346 (59.5%)	49 (60.5%)	297 (59.3%)
Female	236 (40.5%)	32 (39.5%)	204 (40.7%)
Location			
Metropolitan	363 (62.4%)	52(64.2%)	311 (62.1%)
Inner and outer regional areas	95 (16.3%)	10 (12.3%)	85 (17.0%)
Remote and very remote areas	53 (9.1%)	6 (7.4%)	47 (9.4%)
Missing	71 (12.2%)	13 (16.0%)	58 (11.6%)

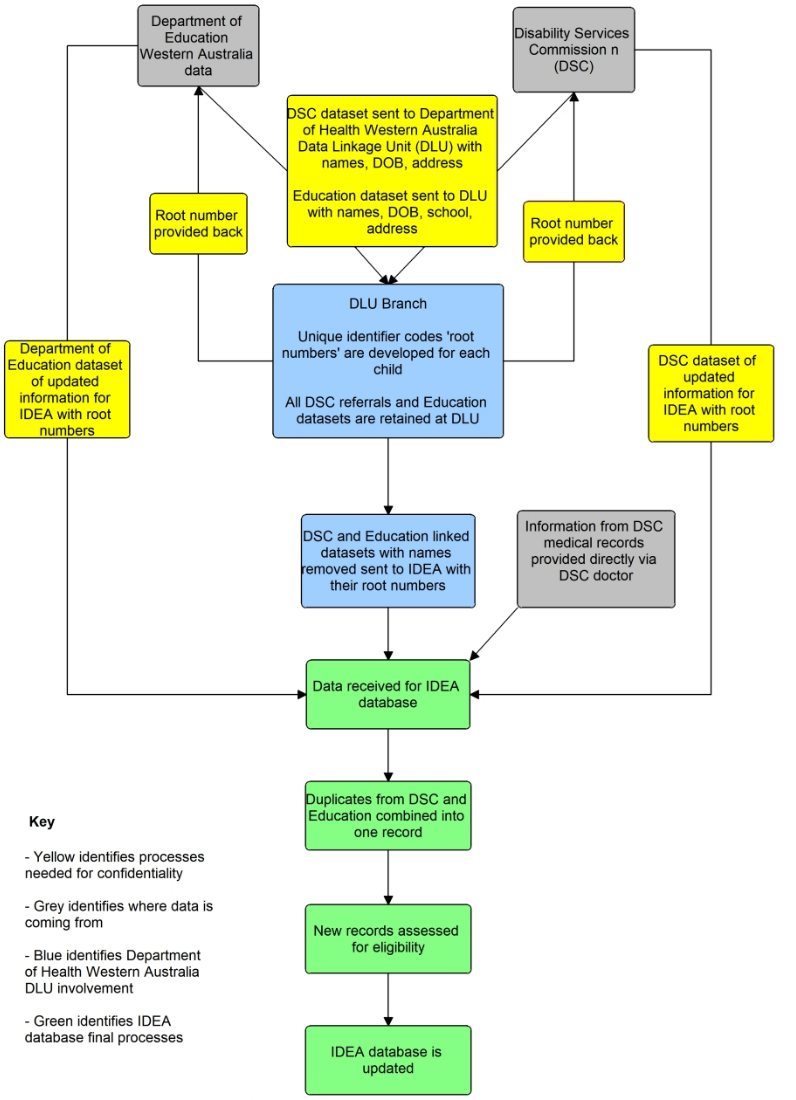
Box 1: Examples of policy and program relevant findings for people living with an intellectual disability

Antenatal care

- Improved management of women with diabetes, epilepsy and/or anaemia during the antenatal period to reduce the risk of having a child with intellectual disabilities.[30]
- Importance of monitoring maternal health due to poor fetal growth increasing the risk of intellectual disability.[31]
- Health promotion and public health campaigns to prevent the use of alcohol during pregnancy.[32]

Service delivery

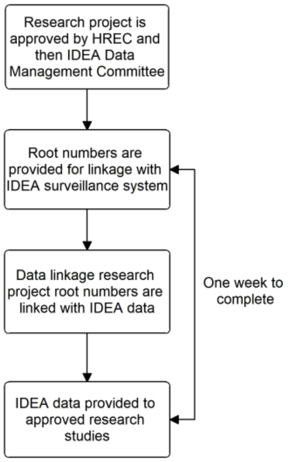
- Children with intellectual disability are also more likely to have birth defects resulting in increased health and social supports for children and additional services for families.[33]
- The need for additional services and support for families in areas of social disadvantage who are at greater risk of having child with intellectual disability.[31]
- Improved access, quality and coordination is needed for individuals with intellectual disability as they are more likely to experience potentially preventable conditions at the end of their lives.[26]



NOTE: The processes in yellow, grey and blue take approximately nine months to complete. The process outlined in green takes approximately four months to complete

Flow diagram of process of data collection for IDEA surveillance system

1020x1443mm (72 x 72 DPI)



Internal data linkage process for IDEA surveillance data

1020x1443mm (72 x 72 DPI)

Supplement 1: Intellectual disability case definition

Disability Services Commission [1]

A person is considered to be intellectually disabled if they have scored more than two standard deviations below the mean on a recent formal assessment of intellectual functioning (within the past 3 years); or scored more than two standard deviations below the mean on a recognised measure of adaptive functioning with demonstrated deficits in two or more of the following skill domains conceptual, social or practical; or if their clinical presentation is consistent with an intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.

Department of Education [2]

Intellectual disability is determined through a diagnostic report which has had all components completed within six months and has considered factors such as language, cultural background, learning opportunities, disabilities, motivation and cooperation. Determining intellectual disability includes an assessment of adaptive functioning using both clinical evaluation and standardised assessment with a significant impairment defined as two standard deviations below the mean on a standardised, culturally relevant assessment in at least one domain across multiple environments (e.g. home, school, community and work). Results and interpretations of assessments demonstrate a significant sub-average intellectual functioning of an intelligence quotient <70 on an individually administered appropriate IQ test; and evidence that academic achievement and progress is limited in comparison to age expectations. Prior to 2006 cases were classified as either a “mild or moderate” or “severe” level of intellectual disability. In 2006, the level of ID provided by the Department was modified to represent the child’s educational level of need, rated from 1 (low need) to 5 (high need). The IDEA surveillance data used the educational need (EN) data to estimate the level of intellectual disability. In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and is used to estimate level of intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.

Supplement 2: Data variables for IDEA surveillance system

Variable	Description
Unique ID	Unique identifier that can be used with other data linkage studies
Ascertainment source	Whether cases were ascertained through Department of Communities or Department of Education
IDEA eligibility	Described as Eligible, Eligible EDWA, Eligible Vulnerable, not eligible. 1. Note: "Eligible EDWA" are cases where there is insufficient information from Department of Communities to determine IDEA eligibility but sufficient information from Education is available. 2. "Eligible Vulnerable" are Department of Communities cases where level of ID is unknown but case has been deemed Vulnerable to ID.
ID level	Mild, mild or moderate, moderate, severe, unknown, Unknown but intellectually handicapped, borderline, Not intellectually handicapped
Sex	Male or Female
DOB Month	Month of birth
DOB Year	Year of birth
Client diagnosis	numeric Heber code for diagnosis – up to four can be recorded
Client diagnosis description	text description of diagnosis - up to four can be recorded
Autism Spectrum Disorder identified	Identifies clients with an autism spectrum disorder diagnosis
Cause of ID	Provides the broader group cause of ID if available. Described as biomedical, not medical – unknown, autism spectrum disorder with ID, insufficient information.

Note: ID (intellectual disability) and intellectual handicap are used interchangeably

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EVALUATING THE ATTRIBUTES OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM

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EVALUATING THE ATTRIBUTES OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM

Running title: Evaluation of the IDEA system

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ABSTRACT

Objectives: Our overall aim was to evaluate the Western Australian 'Intellectual Disability Exploring Answers' (IDEA) surveillance system. The primary objective was to evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the system.

Method: The IDEA system was evaluated using process observation, interviews and secondary data analysis of system attributes: usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability. 2001 U.S. Centers for Disease Control and Prevention guidelines were used.

Results: We found that the IDEA system was useful, simple, flexible, acceptable, representative, timely and stable. We compared individuals from the IDEA system (n=10593) to those with cerebral palsy and ID (n=582) from another surveillance system. Of the 582 with cerebral palsy and ID, 501 (86.1%) were in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. There were little differences in cases that were not identified in the IDEA system between Indigenous status, sex and place of residence.

Conclusions: The strengths of the IDEA system include having a high data quality resource contributing to national and international data on ID, strong government support and a dedicated management team. Output from studies linking to IDEA data have had major contributions to the international literature about ID. However, limited resources have prevented it from realising its full potential in relation to translational activities. The IDEA system is a valuable resource to address the needs of people living with ID.

Strengths and limitations of this study

- The methods used are highly acceptable for evaluating surveillance systems.
- We evaluated the system through process observation, interviews and secondary data analysis.
- We assessed the attributes usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability.
- We investigated the completeness of the IDEA system by cross-checking individuals from the mandatory WA Registry of Developmental Anomalies-Cerebral Palsy database with individuals who have intellectual disability.
- We were unable to compare the system attributes positive predictive value and sensitivity due to a lack of primary data.

INTRODUCTION

People living with an intellectual disability (ID) have impaired thought processes, learning, communication, and remembering, which contribute to their overall intelligence including cognition, and language and may affect motor and social abilities. As a result, people with IDs are more likely to suffer from maltreatment as children,[1] have increased co-morbidities,[2] mental health diagnoses[3] and often experience stigmatisation and discrimination resulting in poor access to health services[4] compared to their counterparts who do not have ID. In addition, with advances in health care, many people with ID now have elderly carers or will outlive their carers. Additional government input for care services previously managed by families will be needed in the years to come.[5]

Internationally there are few dedicated public health surveillance systems for ID. Many rely on data from existing state and national surveys, administrative datasets, registries or integrated data systems.[6-8] In Western Australia (WA), the 'Intellectual Disability Exploring Answers' (IDEA) database is a population-based linked data surveillance system which is internationally recognised for its collection of prevalence and incidence data for ID.[9] The IDEA system originated from a dataset of individuals with ID receiving support from the WA government, was established in 1953 and maintained by successive state governments performing this role. In 2002, the IDEA system was moved to the Telethon Kids Institute (TKI, WA) to become a permanent population-based data linkage surveillance system. The original objective of the surveillance system was to provide high-quality, complete and population based information on ID in WA. It was anticipated that this information might be used for the following purposes: monitoring trends and investigating changes in the prevalence of ID, overall and in various subgroups; providing an infrastructure for population-based epidemiological and genetic research into the causes and prevention of ID; providing an infrastructure for research into the health status and service needs of children and adults with ID; allowing the identification of population based subgroups with specific characteristics who might benefit from new scientific advances; evaluating screening programs for prevention of ID; facilitating planning and providing infrastructure for the evaluation of early intervention and therapy programs; and increasing community and professional knowledge about ID.[10]

The Australian National Disability Insurance Scheme (NDIS) has recently been introduced in Australia and provides funding for supports and services for people living with a significant and permanent disability.[11] As a result, the Disability Services Commission (DSC; now Department of Communities) will no longer provide services for people with ID in WA and in the long run will not provide data to IDEA. Currently proof of concept efforts are underway to pilot the process for the IDEA to receive data from the Australian Commonwealth government on people living in Western Australia with ID. In addition, awareness of the current strengths and limitations of the IDEA surveillance system could help stakeholders and data custodians better recognise the need and value of this system in light of current policy initiatives. Therefore, an evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objective was to systematically and objectively evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

METHODS

Design

This evaluation is based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems.[11] We assessed the following system attributes: usefulness (how important is the collection of ID; does it respond to prevention, early detection and evaluation of programs; or improve public health knowledge), simplicity (ease of understanding data processes), flexibility (ability of the system to adapt to changing needs), data quality (is the data complete), acceptability (the willingness of providers to participate in IDEA system processes), representativeness (is the data generalisable to the wider population), timeliness (speed of which data is provided at all stages), and stability (whether resourcing is sufficient). We did not aim to calculate positive predictive value and sensitivity due to lack of primary data to assess these attributes.

Study setting

Case ascertainment and eligibility

Cases are ascertained from the DSC through referrals to assess individuals for eligibility to access disability services. For the Department of Education cases are school aged children who are identified as potentially needing additional teaching support in relation to intellectual functioning and who have been assessed to determine the level of educational support required. Supplement 1 provides case eligibility for both DSC and Department of Education.

Eligibility for IDEA has been extended to children < 6 years old who are considered 'vulnerable' by the DSC when a developmental assessment indicates a likelihood of ID although they are too young to have a formal IQ assessment. These children are included in the database but are reconsidered if assessments become available at school age. This represents only approximately 2% of cases (estimated for birth years 1990–2001).[9] Children identified through the Department of Education were accepted as having an ID unless there is conflicting evidence from DSC.

Case definition

A confirmed case from the DSC is i) an individual with a full IQ<70; ii) evidence of developmental delay at <18 years of age (where evidence is not available but there is no obvious cause for the ID after 18 years of age, it is accepted that the delay was probably present during childhood and the case will be eligible); or iii) where there is no IQ test score available but the child has a known biomedical cause of ID, such as Down syndrome.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was 'mild or moderate' or severe. Subsequent to 2005 and in the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.[9] In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit AAMR system to assign the most appropriate cause of ID to cases[12] which can be later grouped into broader categories.

Management of IDEA system

Currently there is funding provided by the DSC for personnel equivalent to 0.5 FTE and operating costs. Personnel costs cover liaising with departments for data, updating data within the IDEA system, supporting and completing epidemiological studies on ID and responding to requests for data. Operating costs need to cover future fees for data linkage by Department of Health WA. Funds have also provided some support for traditional research outputs such as conference fees and publication costs. However, there has been limited support for work related travel, communication and engagement activities, which have been covered from other sources including a philanthropic donation in 2013. In addition, there is a volunteer community advisory group which consists of researchers, advocates for ID, policy makers and the IDEA system data custodian. The aim of the advisory group is to review and approve projects applying for the use of ID data in their study and to provide support where applicable. Although the advisory committee originally met annually in person, since 2011 communication between members has primarily been through email.

Patient and public involvement

Patient and public involvement were not completed for the study design or the development of outcome measures. A member of the public and an advocacy organisation for intellectual disability were recruited and provided their views on the IDEA system. The results will be disseminated through traditional journal publication, conference presentation and a lay summary, which will be sent to all individuals who participated in the project. We have acknowledged the time stakeholders spent in participating in the study.

Data collection

For privacy and confidentiality reasons there is a limited number of data variables that are collected as part of the IDEA system (Supplement 2). As a population-based data linkage surveillance system these data need to be linked to other WA administrative data collections.

The process of obtaining data for the IDEA system involves data contributions from two WA government departments, the DSC and the Department of Education. Figure 1 provides a flow diagram outlining the process from case ascertainment to finalising the IDEA system updates. Identifiable data on individuals with probable and suspected ID are provided to the Data Linkage Branch, Department of Health WA. These data are de-identified and only linkable through unique codes called root numbers, which are then provided back to the IDEA custodian and to the respective departments. Both departments then provide the IDEA management team with their de-identified datasets and data variables. This process is undertaken to safeguard privacy and confidentiality at all stages and takes approximately nine months to occur. Once the data are received by the IDEA team duplicates are combined into one record, new records are assessed for eligibility and the system updated (Figure 1). This latter process takes approximately four months to complete. Updates from DSC and the Education Department were initially undertaken every two years. However, there was four years between the last two updates (in 2013 and 2017). This delay was associated with the process of IDEA being converted to an Infrastructure Project.

Data analysis

To evaluate the IDEA surveillance system we took a three-pronged approach including process observation, in-depth interviews and secondary data analysis. Interviewees included representatives from the three WA government departments involved in the IDEA system, community representatives and researchers using a 20-item semi-structured questionnaire. The aim of the interview was to discuss the usefulness, simplicity, flexibility, acceptability, timeliness, data quality, representativeness, and stability of the IDEA system through assessing and understanding responses of stakeholders. The questionnaire was administered face-to-face, took between 30-60 minutes and was recorded with participant's consent for further analysis. Some interviewees were not able to answer all questions depending on their level of involvement with the IDEA system. Thematic analysis according to the system attributes was completed.

Secondary data analysis was used to assess the data quality through determining the completeness of data. Cross-checking of individuals born between 1983—2014 from the mandatory WA Registry of Developmental Anomalies-Cerebral Palsy database (WARDA-CP) who have ID to the IDEA system was undertaken. ID for the WARDA-CP database is ascertained through medical records and is updated when a child is 5 years old. If there is no record of ID, the child's medical record will be checked again once they have started school. All confirmed cases from the IDEA system from 1983-2014 were included. Children from the WARDA-CP database were included in the analysis if they had a mild impairment (IQ or development quotient (DQ) 50-69), moderate impairment (IQ/DQ 35-49) or severe impairment (IQ/DQ <35). Cross-tabulations were completed to determine the number of children from the WARDA-CP database that were not identified in the IDEA system. If there was a discrepancy between databases further investigation to determine reasons for missing cases was completed.

Ethics approval

This study was approved by the Department of Health Western Australia Human Research Ethics Committee (2014/24), The University of Western Australia (RA/4/20/4168) and The Australian National University (2017/567). Written consent was provided and all data collected was anonymous.

RESULTS

Characteristics

Eleven interviews were completed. Three individuals were solely involved in reporting, analysing and/or interpreting of ID surveillance data. Two contributed to the data either directly or in an advisory capacity. Six were involved in both of these roles. Interviewees had been involved with the IDEA system for 3-17 years and many of them contributed to the system in a number of different areas (Table 1). Other roles that were identified included administrative support, reporting, communication and translation.

Usefulness

Data on reasons for the importance of identifying and collecting ID data included:

- identifying prevalence and trends in ID
- using data for prevention of ID and to understand causes of ID, and management of care services
- identifying subgroups such as co-morbidity with mental illness, or child neglect for which ID is a very strong risk factor
- measuring and evaluating life outcomes for people with ID by being able to identify them as they move through the service system
- informing policy and practice particularly from a systems perspective for planning and resource allocation particularly as people with ID are the largest single cohort of individuals receiving support through all disability services.

Concern about the stigma associated with identifying people as having an ID was expressed although services, funding and resource allocation decisions are made as a result of these processes. Ensuring appropriate identification was considered an important part of the data collection process.

Interviewees thought the IDEA surveillance system had either met or partially met the overall aim of the IDEA system; to provide high-quality, complete and population based information on ID in WA. The IDEA surveillance system was considered to be an infrastructure which had provided a substantial amount of data to assess trends in the prevalence of ID, investigate health service use for people with ID, evaluate risks associated with having an ID and health and social determinants of ID. However, a major drawback in 2010 was the loss to the database of any information from the Western Australian Midwives database which provides an individual's basic birth data (born WA, race, birthweight etc.). As a result, other than through separate ethically approved data linkage projects, many of which have been undertaken, it is now difficult to provide many routine statistics. The system was also considered to be missing sub-groups of individuals such as the small number of people attending Catholic or independent schools for children born since 1992, individuals who were not receiving services from DSC or those not using the state education system. Additional data variables such as genetic information related to an individual's ID, co-morbidities, and in particular functional capacity, were commonly cited among interviewees as important information for IDEA. Interviewees agreed that evaluations of screening programs for prevention, early intervention or therapy programs for ID, or genetic research into the causes and prevention of ID had not been possible because of lack of availability of data or, if available, the presence of ethical and other constraints to its linkage. Lastly, it was acknowledged that although professional knowledge had increased about ID it was not known what impact this may have had on community awareness.

All interviewees had either used or read about the IDEA data in journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government reports, newsletters, minister reports, book chapters and conferences. There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data. Importantly, IDEA data have been widely used, cited and published in international literature including in international estimates of years lived with disabilities (2010).[13] In addition, many of the 40 journal articles have investigated both the determinants of ID and to associated outcomes like comorbidities and premature mortality. However, there was unanimous agreement that there needs to be more publications, particularly consumer and policy-driven, as well as regular biannual reports. Although there had been direct engagement with the DSC Director General through meetings every 3 months in 2013 facilitated with philanthropic funding to provide information on outcomes, it was considered by many interviewees that there had been little in the way of communicating results to the community and advocacy organisations. It was suggested knowing this information could be beneficial for community groups to advocate with and for families and individuals with ID.

Simplicity

There were conflicting responses when asked about the simplicity of the system. Respondents discussed the process for collecting data for the IDEA surveillance system inconsistently as simple; timely; complex; or taking too long (Figure 1). However, ultimately the process is largely based on safeguarding privacy therefore the nine months it takes for the IDEA team to receive data was deemed by those who have worked with and in the Department of Health to be in line with current data linkage processes. The four months for integrating data received by government departments into the IDEA system was considered reasonable especially as there is only one person working 0.5 full time equivalent (FTE). The process of providing ID data for research projects was also perceived as appropriate and completed in a timely manner (Figure 2).

Flexibility

The IDEA system was relatively flexible to changes in personnel and case definitions. Personnel and process changes have occurred at all stages within the data process, with the exception of the TKI team. The TKI team has largely remained the same since the inception of the system in 2002. As a result the process of data linkage and extraction from the larger dataset received from Department of Health to the TKI team has not been documented to date. Although having a consistent team has created a system that is flexible and stable, as part of good practice and sustainability, developing formalised documented processes would be valuable. Case definitions have also varied with changes in how the Department of Education have recorded ID. These changes have been recorded and the system adapted accordingly for data integrity.

Data quality

There was universal agreement that the system was not complete for ID in WA with people attending Catholic or independent schools and individuals who were not receiving services from DSC likely to be missing from the system. In addition since mid-2014, individuals living in the Perth Hills region who were part of the NDIS pilot location had their data collected by the Australian Commonwealth government rather than the DSC WA.[14] Therefore there will be no data available on newly registered individuals with ID from this location at the next IDEA update.

Data quality is the responsibility of the two departments that assess individuals for ID. Each department has their own assessments for ID, reasons for collecting ID and ways in which the information is used. Ensuring data quality across organisations and that individuals with ID are correctly identified was seen as important for all people involved in collecting and using data.

We also assessed the completeness for individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, from the mandatory reporting surveillance system WARDA-CP. Overall there were 10593 cases of ID in the IDEA system. 582 individuals were identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. Potential reasons for the discrepancies between the two sources were children who had died prior to school entry may not be identified in IDEA (n=8) and that WARDA may be including cases with probable or borderline ID who would not be eligible for IDEA. There were little differences in Indigenous status, sex and place of residence for cases not identified in the IDEA system (Table 2).

Acceptability

There are four organisations (Telethon Kids Institute, Department of Health WA, DSC, Department of Education) within WA that voluntarily participate in the IDEA surveillance system. Unlike other surveillance systems there are no mandatory requirements for case notification and therefore no onus on clinicians and other public health practitioners to participate. The two departments which supply data for the IDEA system do so voluntarily and deem the collection of data to be important. Memoranda of understanding have been signed by DSC and Education with the Department of Health for the release of data. In addition, there is an agreement between Telethon Kids Institute and Department of Education outlining the provision of education data to IDEA and a Grant Agreement between Telethon Kids Institute and DSC.

Representativeness

ID data within the IDEA surveillance system is dependent on individuals being referred (by clinicians, psychologists, allied health, teachers or parents) for services and/or being identified through the public education system. Since the IDEA system does not have mandatory notifications, it is not surprising that there are certain subgroups of individuals who may not be represented. Despite this, there is no other equivalent system elsewhere in Australia and these data have been used as a key data source for ID national estimates.[15] As a result the epidemiology findings are considered generalisable to the larger Australian population.

Timeliness

Overall the timeliness of the data was considered to be appropriate including the two year period between data extractions. The initial nine months for the data linkage process has previously been delayed through new staff having to extract the data from the two departments, resource limitations and priority delays within the departments. These barriers have resulted in delays at all stages of the nine month data extraction. It was also discussed that some of these time delays were the result of ensuring confidentiality, however, this is an important component of the system. Alternatively, it was mentioned that if individuals, organisations and policymakers valued the data then more frequent data extractions could occur.

Stability

Despite being a non-mandatory surveillance system, data has been regularly provided by departments and there has been ongoing funding negotiated. The funding provided has allowed for a 0.5 FTE position which supports personnel and operating costs. However, in-kind support from the TKI Disability team has also supported these activities and the day to day administrative tasks. The limited funding for the database has also restricted the amount of work that can be achieved within the IDEA system. Additional activities could include engaging with stakeholders, translation and communication of findings, use of IDEA data for supporting policy decisions and priority setting. It was estimated by those working directly with the system that 1.5FTE would be enough to complete the technical requirements of the IDEA surveillance system and be able to complete the additional tasks outlined.

DISCUSSION

The IDEA system is the only Australian population-based ID surveillance system and one of few internationally.[16-18] Since 2002, the IDEA system has been successfully funded and maintained by long-term collaborations with two WA departments. This has provided an infrastructure to understand prevalence rates and trends over time for ID, inform resource allocation, identify those at risk of negligence or other adverse events, identify risk and protective factors associated with ID and inform larger international studies on the global burden of disability.[1 13 19-22] Overall, the IDEA system was considered to be flexible, simple, acceptable, representative, timely and stable. However, components within these attributes such as insufficient engagement with stakeholders and community, lack of opportunities for translation and ensuring there is a workforce to deliver these initiatives could be improved.

Due to the IDEA system's data linkage capabilities, data from Western Australian data collections including health, justice and child protection can be linked to determine important and complex associations both cross-sectionally and longitudinally for people living with intellectual disabilities. These data continue to provide important policy and program relevant implications and findings for both Australia and internationally (Box 1). High quality linked administrative data collections for determining adverse outcomes for people living with ID have been used internationally.[23-26] In the UK, an inquiry found people living with an ID were more likely to experience avoidable deaths.[26] Recommendations from this enquiry were to develop a central registration system for people with learning disabilities to ensure they receive appropriate care. Other country examples of using linked administrative data collections to determine the service utilisation and health disparities for people living with ID and those without include Canada[27 28], Scotland[23 29] and the USA[25 30]. Other alternatives to linked administrative data collections for ID include national surveys, registries and hospital data, which have been used for determining prevalence of ID in low and middle income countries.[17] Currently, the IDEA system is valuable for its contribution to the international literature on ID and the burden of ID globally.[13] The use of high quality data is fundamental in dealing with the challenging health and social issues of people living with IDs, with the IDEA system addressing this need.

Many participants thought that sub-groups were missing within the IDEA system, however, this is likely to be a very small percentage of the population. Case ascertainment using two resources is high with previous research showing that between 1983-2003 only 50% of cases were ascertained through the DSC Services, with the remaining 50% from the Department of Education.[31] In addition, when considering the quality and quantity of services provided, as seen in WA, using administrative data sources results in high ascertainment of cases and therefore sound reporting of prevalence rates.[32] When comparing whether the WARDA-CP system had any additional cases not in the IDEA system there was a small percentage of cases missing. This equated to <1% of total cases in the IDEA system and reflects the high quality data source. The IDEA system provides coverage of ID considerably superior to that from other administrative datasets such as the WA Hospital Morbidity Data System.[33] Overall, the completeness of the IDEA system was high when compared to potential missing population data.

A major concern and impetus for completing this evaluation is the roll-out of the NDIS. Pilot trials have been completed across Australia for the NDIS with individual states currently determining the finer details of how the scheme will work. A common perception of the scheme is that not all individuals will need to be assessed for their disability, particularly ID, if they clearly meet the eligibility requirements. Although it is anticipated that data collection will continue, ascertainment of ID will no longer occur through DSC (now Department of Communities). Negotiations are currently underway to develop the protocols for transfer of Commonwealth data to IDEA. It is envisioned that the IDEA Advisory Group will provide support and advice to this process.

The IDEA surveillance system has provided important clinical data on the health and social needs of people living with ID. Despite this there are a number of areas that the IDEA team could undertake to strengthen the system. Based on this evaluation we recommend the following:

1. Discussion and engagement with the IDEA advisory group on the collection of ID given the changes in data ownership.
2. The IDEA team has been involved in the system since its initiation in 2002. As a result there have been few protocols developed for how data are linked, extracted and maintained. It is recommended that internal protocols are developed for future personnel working on the system. An additional 1FTE is also recommended to support additional activities proposed in these recommendations.
3. Active engagement with community and relevant stakeholders including disability organisations, policy makers, researchers and service organisations is sorely needed to promote awareness of current research and to determine priority setting for future research. This can be achieved

through the development of communication and translation strategies as well as priority setting workshops.

4. Currently the IDEA team uses the Heber classification for the level of disability. This is an outdated system with other classification systems more up to date with current practice. Determining whether there are other classification systems that could be used and if the data could be moved to this system would be beneficial.
5. An additional variable for functional ability was considered to be important for informing current practice. Enhanced surveillance on a sub-group of individuals could be considered. To determine whether these data are important and if so what data would be included should occur in consultation with stakeholders.
6. The community advisory group should consider meeting annually again. This increased level of active engagement and strategic planning could influence the current activities of IDEA and inform future directions. Leadership is needed and the community advisory group are well placed to take on this role.

CONCLUSION

The IDEA surveillance system provides crucial data about people living with ID. However, there remains significant challenges in the future of the IDEA system given recent funding and service delivery changes within Australia. Changes to engagement with the community and stakeholders could play an essential role in the sustainability of the IDEA system through advocacy for its continuation. Enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families. The IDEA surveillance system is one of the few international ongoing data collections of ID. Discontinuing data collection and evaluation for this vulnerable population would be a disservice to society. Implementation of these recommendations will provide ways for the IDEA system to remain a successful source of important data for people living in with an ID.

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AUTHOR CONTRIBUTIONS

Conceived and designed the experiments: NS, JB, HL, AR, DM. Performed the experiments: NS, JB. Analysed the data: NS. Wrote and provided intellectual input into the paper: NS JB, HL, AR, KE, DM. All authors approved the final version. All authors are accountable for all aspects of the paper.

COMPETING INTERESTS

Author JB is employed to work on the IDEA system. Author HL is the data custodian of the IDEA system.

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DATA SHARING STATEMENT

Data are available through ethical approval from the relevant ethics committees in collaboration with the authors.

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FIGURE LEGENDS

Figure 1: Flow diagram of process of data collection for IDEA surveillance system

Figure 2: Internal data linkage process for IDEA surveillance data

Table 1: Roles identified by interviewees within the IDEA surveillance system

Characteristics	Numbers (%)*
Analysing data	8 (73%)
Reporting data	8 (73%)
Interpreting data	9 (82%)
Maintenance of data	5 (45%)
Data quality	7 (64%)
Committee member	4 (36%)
Data entry	3 (27%)
Data linkage	3 (27%)
Data extraction	3 (27%)
Management of data	6 (55%)
Advocacy	5 (45%)

*The are multiple counts

Table 2: Comparison of IDEA and WARDA-CP surveillance system data, 1982-2014

Variable	Total in WARDA-CP (n) %	Not in IDEA system (n) %	In both surveillance systems n (%)
Total	582	81 (13.9%)	501 (86.1%)
Alive	470 (80.8%)	69 (85.2%)	401 (80.0%)
Deceased	112 (19.2%)	12 (14.8%)	100 (20.0 %)
Indigenous status			
Indigenous	80 (13.7%)	15 (18.5%)	65 (13.0%)
Non-Indigenous	502 (86.3%)	66 (81.5%)	436 (87.0%)
Sex			
Male	346 (59.5%)	49 (60.5%)	297 (59.3%)
Female	236 (40.5%)	32 (39.5%)	204 (40.7%)
Location			
Metropolitan	363 (62.4%)	52(64.2%)	311 (62.1%)
Inner and outer regional areas	95 (16.3%)	10 (12.3%)	85 (17.0%)
Remote and very remote areas	53 (9.1%)	6 (7.4%)	47 (9.4%)
Missing	71 (12.2%)	13 (16.0%)	58 (11.6%)

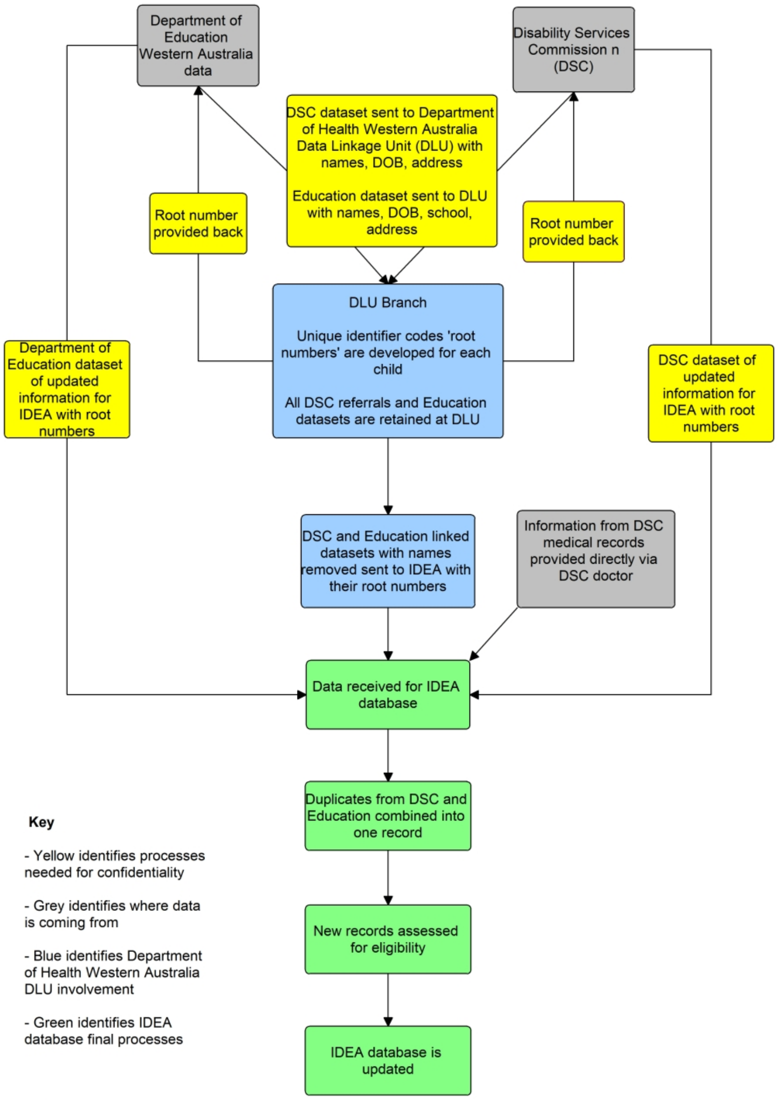
Box 1: Examples of policy and program relevant findings for people living with an intellectual disability

Antenatal care

- Improved management of women with diabetes, epilepsy and/or anaemia during the antenatal period to reduce the risk of having a child with intellectual disabilities.[34]
- Importance of monitoring maternal health due to poor fetal growth increasing the risk of intellectual disability.[35]
- Health promotion and public health campaigns to prevent the use of alcohol during pregnancy.[36]

Service delivery

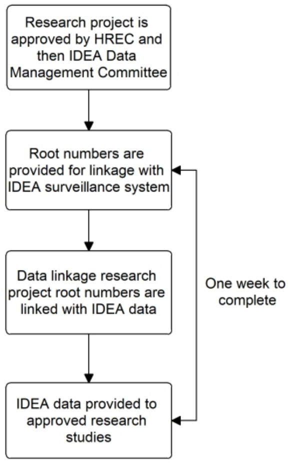
- Children with intellectual disability are also more likely to have birth defects resulting in increased health and social supports for children and additional services for families.[37]
- The need for additional services and support for families in areas of social disadvantage who are at greater risk of having child with intellectual disability.[35]
- Improved access, quality and coordination is needed for individuals with intellectual disability as they are more likely to experience potentially preventable conditions at the end of their lives.[38]



NOTE: The processes in yellow, grey and blue take approximately nine months to complete. The process outlined in green takes approximately four months to complete

Flow diagram of process of data collection for IDEA surveillance system

1166x1649mm (72 x 72 DPI)



Internal data linkage process for IDEA surveillance data

1166x1649mm (72 x 72 DPI)

Supplement 1: Intellectual disability case definition

Disability Services Commission [1]

A person is considered to be intellectually disabled if they have scored more than two standard deviations below the mean on a recent formal assessment of intellectual functioning (within the past 3 years); or scored more than two standard deviations below the mean on a recognised measure of adaptive functioning with demonstrated deficits in two or more of the following skill domains conceptual, social or practical; or if their clinical presentation is consistent with an intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.

Department of Education [2]

Intellectual disability is determined through a diagnostic report which has had all components completed within six months and has considered factors such as language, cultural background, learning opportunities, disabilities, motivation and cooperation. Determining intellectual disability includes an assessment of adaptive functioning using both clinical evaluation and standardised assessment with a significant impairment defined as two standard deviations below the mean on a standardised, culturally relevant assessment in at least one domain across multiple environments (e.g. home, school, community and work). Results and interpretations of assessments demonstrate a significant sub-average intellectual functioning of an intelligence quotient <70 on an individually administered appropriate IQ test; and evidence that academic achievement and progress is limited in comparison to age expectations. Prior to 2006 cases were classified as either a “mild or moderate” or “severe” level of intellectual disability. In 2006, the level of ID provided by the Department was modified to represent the child’s educational level of need, rated from 1 (low need) to 5 (high need). The IDEA surveillance data used the educational need (EN) data to estimate the level of intellectual disability. In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and is used to estimate level of intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.

Supplement 2: Data variables for IDEA surveillance system

Variable	Description
Unique ID	Unique identifier that can be used with other data linkage studies
Ascertainment source	Whether cases were ascertained through Department of Communities or Department of Education
IDEA eligibility	Described as Eligible, Eligible EDWA, Eligible Vulnerable, not eligible. 1. Note: “Eligible EDWA” are cases where there is insufficient information from Department of Communities to determine IDEA eligibility but sufficient information from Education is available. 2. “Eligible Vulnerable” are Department of Communities cases where level of ID is unknown but case has been deemed Vulnerable to ID.
ID level	Mild, mild or moderate, moderate, severe, unknown, Unknown but intellectually handicapped, borderline, Not intellectually handicapped
Sex	Male or Female
DOB Month	Month of birth
DOB Year	Year of birth
Client diagnosis	numeric Heber code for diagnosis – up to four can be recorded
Client diagnosis description	text description of diagnosis - up to four can be recorded
Autism Spectrum Disorder identified	Identifies clients with an autism spectrum disorder diagnosis
Cause of ID	Provides the broader group cause of ID if available. Described as biomedical, not medical – unknown, autism spectrum disorder with ID, insufficient information.

Note: ID (intellectual disability) and intellectual handicap are used interchangeably

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ASSESSING THE QUALITY, EFFICIENCY AND USEFULNESS OF THE WESTERN AUSTRALIAN POPULATION BASED INTELLECTUAL DISABILITY EXPLORING ANSWERS (IDEA) SURVEILLANCE SYSTEM: A SURVEILLANCE SYSTEM EVALUATION

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Running title: Evaluation of the IDEA system

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ABSTRACT

Objectives: Our overall aim was to evaluate the Western Australian 'Intellectual Disability Exploring Answers' (IDEA) surveillance system. The primary objective was to evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the system.

Method: The IDEA system was evaluated using process observation, interviews and secondary data analysis of system attributes: usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability. 2001 U.S. Centers for Disease Control and Prevention guidelines were used.

Results: We found that the IDEA system was useful, simple, flexible, acceptable, representative, timely and stable. We compared individuals from the IDEA system (n=10593) to those with cerebral palsy and ID (n=582) from another surveillance system. Of the 582 with cerebral palsy and ID, 501 (86.1%) were in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. There were little differences in cases that were not identified in the IDEA system between Indigenous status, sex and place of residence.

Conclusions: The strengths of the IDEA system include having a high data quality resource contributing to national and international data on ID, strong government support and a dedicated management team. Output from studies linking to IDEA data have had major contributions to the international literature about ID. However, limited resources have prevented it from realising its full potential in relation to translational activities. The IDEA system is a valuable resource to address the needs of people living with ID.

Strengths and limitations of this study

- The methods used are highly acceptable for evaluating surveillance systems.
- We evaluated the system through process observation, interviews and secondary data analysis.
- We assessed the attributes usefulness, simplicity, data quality, acceptability, representativeness, timeliness, and stability.
- We investigated the completeness of the IDEA system by cross-checking individuals from the mandatory Western Australian Registry of Developmental Anomalies-Cerebral Palsy database with individuals who have intellectual disability.
- We were unable to compare the system attributes positive predictive value and sensitivity due to a lack of primary data.

INTRODUCTION

People living with an intellectual disability (ID) have impaired thought processes, learning, communication, and remembering, which contribute to their overall intelligence including cognition, and language and may affect motor and social abilities. As a result, people with IDs are more likely to suffer from maltreatment as children,[1] have increased co-morbidities,[2] mental health diagnoses[3] and often experience stigmatisation and discrimination resulting in poor access to health services[4] compared to their counterparts who do not have ID. In addition, with advances in health care, many people with ID now have elderly carers or will outlive their carers. Additional government input for care services previously managed by families will be needed in the years to come.[5]

Internationally there are few dedicated public health surveillance systems for ID. Many rely on data from existing state and national surveys, administrative datasets, registries or integrated data systems.[6-8] In Western Australia, the 'Intellectual Disability Exploring Answers' (IDEA) database is a population-based linked data surveillance system which is internationally recognised for its collection of prevalence and incidence data for ID.[9] The original objective of the surveillance system was to provide high-quality, complete and population based information on ID in Western Australia. It was anticipated that this information might be used for the following purposes: monitoring trends and investigating changes in the prevalence of ID, overall and in various subgroups; providing an infrastructure for population-based epidemiological and genetic research into the causes and prevention of ID; providing an infrastructure for research into the health status and service needs of children and adults with ID; allowing the identification of population based subgroups with specific characteristics who might benefit from new scientific advances; evaluating screening programs for prevention of ID; facilitating planning and providing infrastructure for the evaluation of early intervention and therapy programs; and increasing community and professional knowledge about ID.[10]

The Australian National Disability Insurance Scheme has recently been introduced in Australia and provides funding for supports and services for people living with a significant and permanent disability.[11] As a result, the Disability Services Commission (DSC; now Department of Communities) will no longer provide services for people with ID in Western Australia and in the long run will not provide data to IDEA. Currently proof of concept efforts are underway to pilot the process for the IDEA to receive data from the Australian Commonwealth government on people living in Western Australia with ID. In addition, awareness of the current strengths and limitations of the IDEA surveillance system could help stakeholders and data custodians better recognise the need and value of this system in light of current policy initiatives. Therefore, an evaluation of the IDEA surveillance system was undertaken to assess the quality, efficiency and usefulness of the system. The primary objective was to systematically and objectively evaluate the attributes of the system. The secondary objective was to provide recommendations to data custodians and stakeholders to strengthen the surveillance system.

METHODS

Design

This evaluation is based on the methods from the 2001 U.S. Centers for Disease Control and Prevention guidelines on evaluation of public health surveillance systems.[11] We assessed the following system attributes: usefulness (how important is the collection of ID; does it respond to prevention, early detection and evaluation of programs; or improve public health knowledge), simplicity (ease of understanding data processes), flexibility (ability of the system to adapt to changing needs), data quality (is the data complete), acceptability (the willingness of providers to participate in IDEA system processes), representativeness (is the data generalisable to the wider population), timeliness (speed of which data is provided at all stages), and stability (whether resourcing is sufficient). We did not aim to calculate positive predictive value and sensitivity due to lack of primary data to assess these attributes.

Study setting

Case ascertainment and eligibility

Cases are ascertained from the DSC through referrals to assess individuals for eligibility to access disability services. For the Department of Education cases are school aged children who are identified as potentially needing additional teaching support in relation to intellectual functioning and who have been assessed to determine the level of educational support required. The supplementary material provides case eligibility for both DSC and Department of Education.

Eligibility for IDEA has been extended to children < 6 years old who are considered 'vulnerable' by the DSC when a developmental assessment indicates a likelihood of ID although they are too young to have a formal IQ assessment. These children are included in the database but are reconsidered if assessments become available at school age. This represents only approximately 2% of cases (estimated for birth years 1990–2001).[9] Children identified through the Department of Education were accepted as having an ID unless there is conflicting evidence from DSC.

Case definition

A confirmed case from the DSC is i) an individual with a full IQ<70; ii) evidence of developmental delay at <18 years of age (where evidence is not available but there is no obvious cause for the ID after 18 years of age, it is accepted that the delay was probably present during childhood and the case will be eligible); or iii) where there is no IQ test score available but the child has a known biomedical cause of ID, such as Down syndrome.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was 'mild or moderate' or severe. Subsequent to 2005 and in the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.[9] In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit AAMR system to assign the most appropriate cause of ID to cases[12] which can be later grouped into broader categories.

Management of IDEA system

Currently there is funding provided by the DSC for personnel equivalent to 0.5 FTE and operating costs. Personnel costs cover liaising with departments for data, updating data within the IDEA system, supporting and completing epidemiological studies on ID and responding to requests for data. Operating costs need to cover future fees for data linkage by Department of Health Western Australia. Funds have also provided some support for traditional research outputs such as conference fees and publication costs. However, there has been limited support for work related travel, communication and engagement activities, which have been covered from other sources including a philanthropic donation in 2013. In addition, there is a volunteer community advisory group which consists of researchers, advocates for ID, policy makers and the IDEA system data custodian. The aim of the advisory group is to review and approve projects applying for the use of ID data in their study and to provide support where applicable. Although the advisory committee originally met annually in person, since 2011 communication between members has primarily been through email.

Patient and public involvement

Patient and public involvement were not completed for the study design or the development of outcome measures. A member of the public and an advocacy organisation for intellectual disability were recruited and provided their views on the IDEA system. The results will be disseminated through traditional journal publication, conference presentation and a lay summary, which will be sent to all individuals who participated in the project. We have acknowledged the time stakeholders spent in participating in the study.

Data collection

For privacy and confidentiality reasons there is a limited number of data variables that are collected as part of the IDEA system (Supplement Table 1). As a population-based data linkage surveillance system these data need to be linked to other Western Australian administrative data collections.

The process of obtaining data for the IDEA system involves data contributions from two Western Australian government departments, the DSC and the Department of Education. Figure 1 provides a flow diagram outlining the process from case ascertainment to finalising the IDEA system updates. Identifiable data on individuals with probable and suspected ID are provided to the Data Linkage Branch, Department of Health Western Australia. These data are de-identified and only linkable through unique codes called root numbers, which are then provided back to the IDEA custodian and to the respective departments. Both departments then provide the IDEA management team with their de-identified datasets and data variables. This process is undertaken to safeguard privacy and confidentiality at all stages and takes approximately nine months to occur. Once the data are received by the IDEA team duplicates are combined into one record, new records are assessed for eligibility and the system updated (Figure 1). This latter process takes approximately four months to complete. Updates from DSC and the Education Department were initially undertaken every two years. However, there was four years between the last two updates (in 2013 and 2017). This delay was associated with the process of IDEA being converted to an Infrastructure Project.

Data analysis

To evaluate the IDEA surveillance system we took a three-pronged approach including process observation, in-depth interviews and secondary data analysis. Interviewees included representatives from the three Western Australian government departments involved in the IDEA system, community representatives and researchers using a 20-item semi-structured questionnaire. The aim of the interview was to discuss the usefulness, simplicity, flexibility, acceptability, timeliness, data quality, representativeness, and stability of the IDEA system through assessing and understanding responses of stakeholders. The questionnaire was administered face-to-face, took between 30-60 minutes and was recorded with participant’s consent for further analysis. Some interviewees were not able to answer all questions depending on their level of involvement with the IDEA system. Thematic analysis according to the system attributes was completed.

Secondary data analysis was used to assess the data quality through determining the completeness of data. Cross-checking of individuals born between 1983—2014 from the mandatory Western Australian Registry of Developmental Anomalies-Cerebral Palsy database (WARDA-CP) who have ID to the IDEA system was undertaken. ID for the WARDA-CP database is ascertained through medical records and is updated when a child is 5 years old. If there is no record of ID, the child’s medical record will be checked again once they have started school. All confirmed cases from the IDEA system from 1983-2014 were included. Children from the WARDA-CP database were included in the analysis if they had a mild impairment (IQ or development quotient (DQ) 50-69), moderate impairment (IQ/DQ 35-49) or severe impairment (IQ/DQ <35). Cross-tabulations were completed to determine the number of children from the WARDA-CP database that were not identified in the IDEA system. If there was a discrepancy between databases further investigation to determine reasons for missing cases was completed.

Ethics approval

This study was approved by the Department of Health Western Australia Human Research Ethics Committee (2014/24), The University of Western Australia (RA/4/20/4168) and The Australian National University (2017/567). Written consent was provided and all data collected was anonymous.

RESULTS

Characteristics

Eleven interviews were completed. Three individuals were solely involved in reporting, analysing and/or interpreting of ID surveillance data. Two contributed to the data either directly or in an advisory capacity. Six were involved in both of these roles. Interviewees had been involved with the IDEA system for 3-17 years and many of them contributed to the system in a number of different areas (Table 1). Other roles that were identified included administrative support, reporting, communication and translation.

Usefulness

Data on reasons for the importance of identifying and collecting ID data included:

- identifying prevalence and trends in ID
- using data for prevention of ID and to understand causes of ID, and management of care services
- identifying subgroups such as co-morbidity with mental illness, or child neglect for which ID is a very strong risk factor
- measuring and evaluating life outcomes for people with ID by being able to identify them as they move through the service system
- informing policy and practice particularly from a systems perspective for planning and resource allocation particularly as people with ID are the largest single cohort of individuals receiving support through all disability services.

Concern about the stigma associated with identifying people as having an ID was expressed although services, funding and resource allocation decisions are made as a result of these processes. Ensuring appropriate identification was considered an important part of the data collection process.

Interviewees thought the IDEA surveillance system had either met or partially met the overall aim of the IDEA system; to provide high-quality, complete and population based information on ID in Western Australia. The IDEA surveillance system was considered to be an infrastructure which had provided a substantial amount of data to assess trends in the prevalence of ID, investigate health service use for people with ID, evaluate risks associated with having an ID and health and social determinants of ID. However, a major drawback in 2010 was the loss to the database of any information from the Western Australian Midwives database which provides an individual's basic birth data (born in Western Australia, race, birthweight etc.). As a result, other than through separate ethically approved data linkage projects, many of which have been undertaken, it is now difficult to provide many routine statistics. The system was also considered to be missing sub-groups of individuals such as the small number of people attending Catholic or independent schools for children born since 1992, individuals who were not receiving services from DSC or those not using the state education system. Additional data variables such as genetic information related to an individual's ID, co-morbidities, and in particular functional capacity, were commonly cited among interviewees as important information for IDEA. Interviewees agreed that evaluations of screening programs for prevention, early intervention or therapy programs for ID, or genetic research into the causes and prevention of ID had not been possible because of lack of availability of data or, if available, the presence of ethical and other constraints to its linkage. Lastly, it was acknowledged that although professional knowledge had increased about ID it was not known what impact this may have had on community awareness.

All interviewees had either used or read about the IDEA data in journal publications, annual reports, stakeholder reports, reports for consumers or the public, policy briefs, government reports, newsletters, minister reports, book chapters and conferences. There have been over 40 journal publications with approximately 740 citations and 70 conference presentations between 2004-2017 that have used IDEA surveillance data. Importantly, IDEA data have been widely used, cited and published in international literature including in international estimates of years lived with disabilities

(2010).[13] In addition, many of the 40 journal articles have investigated both the determinants of ID and to associated outcomes like comorbidities and premature mortality. However, there was unanimous agreement that there needs to be more publications, particularly consumer and policy-driven, as well as regular biannual reports. Although there had been direct engagement with the DSC Director General through meetings every 3 months in 2013 facilitated with philanthropic funding to provide information on outcomes, it was considered by many interviewees that there had been little in the way of communicating results to the community and advocacy organisations. It was suggested knowing this information could be beneficial for community groups to advocate with and for families and individuals with ID.

Simplicity

There were conflicting responses when asked about the simplicity of the system. Respondents discussed the process for collecting data for the IDEA surveillance system inconsistently as simple; timely; complex; or taking too long (Figure 1). However, ultimately the process is largely based on safeguarding privacy therefore the nine months it takes for the IDEA team to receive data was deemed by those who have worked with and in the Department of Health to be in line with current data linkage processes. The four months for integrating data received by government departments into the IDEA system was considered reasonable especially as there is only one person working 0.5 full time equivalent (FTE). The process of providing ID data for research projects was also perceived as appropriate and completed in a timely manner (Figure 2).

Flexibility

The IDEA system was relatively flexible to changes in personnel and case definitions. Personnel and process changes have occurred at all stages within the data process, with the exception of the TKI team. The TKI team has largely remained the same since the inception of the system in 2002. As a result the process of data linkage and extraction from the larger dataset received from Department of Health to the TKI team has not been documented to date. Although having a consistent team has created a system that is flexible and stable, as part of good practice and sustainability, developing formalised documented processes would be valuable. Case definitions have also varied with changes in how the Department of Education have recorded ID. These changes have been recorded and the system adapted accordingly for data integrity.

Data quality

There was universal agreement that the system was not complete for ID in Western Australia with people attending Catholic or independent schools and individuals who were not receiving services from DSC likely to be missing from the system. In addition since mid-2014, individuals living in the Perth Hills region who were part of the National Disability Insurance Scheme pilot location had their data collected by the Australian Commonwealth government rather than the state based government.[14] Therefore there will be no data available on newly registered individuals with ID from this location at the next IDEA update.

Data quality is the responsibility of the two departments that assess individuals for ID. Each department has their own assessments for ID, reasons for collecting ID and ways in which the information is used. Ensuring data quality across organisations and that individuals with ID are correctly identified was seen as important for all people involved in collecting and using data.

We also assessed the completeness for individuals in the IDEA surveillance system to a sub-group of individuals, cerebral palsy with ID, from the mandatory reporting surveillance system WARDA-CP. Overall there were 10593 cases of ID in the IDEA system. 582 individuals were identified in the WARDA-CP surveillance system as having cerebral palsy and ID. Of those identified 501 (86.1%) were also in the IDEA system and 81 (13.9%) were not. In total 0.7% of cases (81/10674) with ID were not identified in the IDEA system. Potential reasons for the discrepancies between the two sources were children who had died prior to school entry may not be identified in IDEA (n=8) and that WARDA may be including cases with probable or borderline ID who would not be eligible for

IDEA. There were little differences in Indigenous status, sex and place of residence for cases not identified in the IDEA system (Table 2).

Acceptability

There are four organisations (Telethon Kids Institute, Department of Health Western Australia, DSC, Department of Education) within Western Australia that voluntarily participate in the IDEA surveillance system. Unlike other surveillance systems there are no mandatory requirements for case notification and therefore no onus on clinicians and other public health practitioners to participate. The two departments which supply data for the IDEA system do so voluntarily and deem the collection of data to be important. Memoranda of understanding have been signed by DSC and Education with the Department of Health for the release of data. In addition, there is an agreement between Telethon Kids Institute and Department of Education outlining the provision of education data to IDEA and a Grant Agreement between Telethon Kids Institute and DSC.

Representativeness

ID data within the IDEA surveillance system is dependent on individuals being referred (by clinicians, psychologists, allied health, teachers or parents) for services and/or being identified through the public education system. Since the IDEA system does not have mandatory notifications, it is not surprising that there are certain subgroups of individuals who may not be represented. Despite this, there is no other equivalent system elsewhere in Australia and these data have been used as a key data source for ID national estimates.[15] As a result the epidemiology findings are considered generalisable to the larger Australian population.

Timeliness

Overall the timeliness of the data was considered to be appropriate including the two year period between data extractions. The initial nine months for the data linkage process has previously been delayed through new staff having to extract the data from the two departments, resource limitations and priority delays within the departments. These barriers have resulted in delays at all stages of the nine month data extraction. It was also discussed that some of these time delays were the result of ensuring confidentiality, however, this is an important component of the system. Alternatively, it was mentioned that if individuals, organisations and policymakers valued the data then more frequent data extractions could occur.

Stability

Despite being a non-mandatory surveillance system, data has been regularly provided by departments and there has been ongoing funding negotiated. The funding provided has allowed for a 0.5 FTE position which supports personnel and operating costs. However, in-kind support from the TKI Disability team has also supported these activities and the day to day administrative tasks. The limited funding for the database has also restricted the amount of work that can be achieved within the IDEA system. Additional activities could include engaging with stakeholders, translation and communication of findings, use of IDEA data for supporting policy decisions and priority setting. It was estimated by those working directly with the system that 1.5FTE would be enough to complete the technical requirements of the IDEA surveillance system and be able to complete the additional tasks outlined.

DISCUSSION

The IDEA system is the only Australian population-based ID surveillance system and one of few internationally.[16-18] Since 2002, the IDEA system has been successfully funded and maintained by long-term collaborations with two Western Australian departments. This has provided an infrastructure to understand prevalence rates and trends over time for ID, inform resource allocation, identify those at risk of negligence or other adverse events, identify risk and protective factors associated with ID and inform larger international studies on the global burden of disability.[1 13 19-22] Overall, the IDEA system was considered to be flexible, simple, acceptable, representative, timely and stable. However, components within these attributes such as insufficient engagement with stakeholders and community, lack of opportunities for translation and ensuring there is a workforce to deliver these initiatives could be improved.

Although many participants thought that sub-groups were missing within the IDEA system, this is likely to be a very small percentage of the population. Case ascertainment using two resources is high with previous research showing that between 1983-2003 only 50% of cases were ascertained through the DSC Services, with the remaining 50% from the Department of Education.[23] In addition, when considering the quality and quantity of services provided, as seen in Western Australia, using administrative data sources results in high ascertainment of cases and therefore sound reporting of prevalence rates.[24] When comparing whether the WARDA-CP system had any additional cases not in the IDEA system there was a small percentage of cases missing. This equated to <1% of total cases in the IDEA system and reflects the high quality data source. The IDEA system provides coverage of ID considerably superior to that from other administrative datasets such as the Western Australia Hospital Morbidity Data System.[25] Overall, the completeness of the IDEA system was high when compared to potential missing population data.

Due to the IDEA system's data linkage capabilities, data from Western Australian data collections including health, justice and child protection can be linked to determine important and complex associations both cross-sectionally and longitudinally for people living with intellectual disabilities. High quality linked administrative data collections for determining adverse outcomes for people living with ID have been used internationally.[26-29] In the UK, an inquiry found people living with an ID were more likely to experience avoidable deaths.[29] Recommendations from this enquiry were to develop a central registration system for people with learning disabilities to ensure they receive appropriate care. Other country examples of using linked administrative data collections to determine the service utilisation and health disparities for people living with ID and those without include Canada[30 31], Scotland[26 32] and the USA[28 33].

Current and future impact of ID data

In Australia, the methods for capturing and reporting on ID are some of the best in the world. Aside from Canada, the Western Australian IDEA systems infrastructure and data linkage capabilities has resulted in one of the largest repositories of data.[34] Data has been used, but not limited to identifying important health disparities, psychiatric co-morbidities and health service patterns, including the last year of life among people living with an ID.[20 35 36] IDEA data has also contributed to prevalence patterns, identifying increased mortality risk for children at different ages and the burden of ID globally.[13 19 22] Box 1 provides a summary of important policy and program relevant implications and findings for both Australia and internationally.

More recently, research published using IDEA data has shown that children with an ID were at higher risk of child maltreatment allegations compared to children without a disability.[1] These results have been reported by researchers from the Telethon Kids Institute to the Australian Royal Commission into Institutional Responses to Child Sexual Abuse in regards to identifying the prevalence of child sexual abuse among children with disabilities.[37] In addition, these data were also used to advocate and successfully implement a disability indicator within the Western Australia Department of Communities – Child Protection and Family Support and the Australian National Child Protection Minimum Dataset in order to improve the detection and management of children with an intellectual disability who have experienced maltreatment.[37] This indicator will also assist in the development of maltreatment prevention strategies for children with an ID. Examples such as these demonstrate how high quality data is fundamental in dealing with the challenging health and social issues of people living with IDs.

Although there has been substantial work completed in the local context for people living with an ID there is still more that the IDEA system can contribute too internationally. There are still large gaps in the evidence including understanding mortality rates among those with intellectual disabilities including using consistent methodology and cases definition, differentiating between specific syndromes and creating pooled mortality estimates from different countries through virtual minimum datasets to determine the global mortality rate attributed to ID. The IDEA system is well set up to contribute to these important local and international research priorities.

Lessons learnt

There are two main indicators that have resulted in the success of the IDEA system. The first is the vision and leadership of data custodians and those who saw the immense value of having a population-based data collection for ID. These individuals have made substantial contributions to research and policy translation of people living with an ID in Western Australia. The second is Western Australia's high quality data linkage system, which helped them make their vision become a reality. Although other governments may not be able to achieve this level of population based data linkage other alternative data collections exist such as national surveys, registries and hospital data. These alternatives have been used for determining prevalence of ID in low and middle income countries, which have also made important contributions to ID data.[17]

Recommendations

The IDEA surveillance system has provided important clinical data on the health and social needs of people living with ID. Despite this there are a number of areas that the IDEA team could undertake to strengthen the system. Based on this evaluation we recommend the following:

1. Discussion and engagement with the IDEA Advisory Group on the collection of ID given the changes in data ownership.
2. The IDEA team has been involved in the system since its initiation in 2002. As a result there have been few protocols developed for how data are linked, extracted and maintained. It is recommended that internal protocols are developed for future personnel working on the system. An additional 1FTE is also recommended to support additional activities proposed in these recommendations.
3. Active engagement with community and relevant stakeholders including disability organisations, policy makers, researchers and service organisations is sorely needed to promote awareness of current research and to determine priority setting for future research. This can be achieved

through the development of communication and translation strategies as well as priority setting workshops.

4. Currently the IDEA team uses the Heber classification for the level of disability. This is an outdated system with other classification systems more up to date with current practice. Determining whether there are other classification systems that could be used and if the data could be moved to this system would be beneficial.
5. An additional variable for functional ability was considered to be important for informing current practice. Enhanced surveillance on a sub-group of individuals could be considered. To determine whether these data are important and if so what data would be included should occur in consultation with stakeholders.
6. The Advisory Group should consider meeting annually again. This increased level of active engagement and strategic planning could influence the current activities of IDEA and inform future directions. Leadership is needed and the Advisory Group are well placed to take on this role.

CONCLUSION

The IDEA surveillance system provides crucial data about people living with ID. However, there remains significant challenges in the future of the IDEA system given recent funding and service delivery changes within Australia. Changes to engagement with the community and stakeholders could play an essential role in the sustainability of the IDEA system through advocacy for its continuation. Enhanced surveillance for functional capacity could also strengthen the system and provide important information for people living with ID and their families. The IDEA surveillance system is one of the few international ongoing data collections of ID. Discontinuing data collection and evaluation for this vulnerable population would be a disservice to society. Implementation of these recommendations will provide ways for the IDEA system to remain a successful source of important data for people living in with an ID.

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AUTHOR CONTRIBUTIONS

Conceived and designed the experiments: NS, JB, HL, AR, DM. Performed the experiments: NS, JB. Analysed the data: NS. Wrote and provided intellectual input into the paper: NS JB, HL, AR, KE, DM. All authors approved the final version. All authors are accountable for all aspects of the paper.

COMPETING INTERESTS

Author JB is employed to work on the IDEA system. Author HL is the data custodian of the IDEA system.

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DATA SHARING STATEMENT

Data are available through ethical approval from the relevant ethics committees in collaboration with the authors.

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FIGURE LEGENDS

Figure 1: Flow diagram of process of data collection for IDEA surveillance system

Figure 2: Internal data linkage process for IDEA surveillance data

Table 1: Roles identified by interviewees within the IDEA surveillance system

Characteristics	Numbers (%)*
Analysing data	8 (73%)
Reporting data	8 (73%)
Interpreting data	9 (82%)
Maintenance of data	5 (45%)
Data quality	7 (64%)
Committee member	4 (36%)
Data entry	3 (27%)
Data linkage	3 (27%)
Data extraction	3 (27%)
Management of data	6 (55%)
Advocacy	5 (45%)

*The are multiple counts

Table 2: Comparison of IDEA and WARDA-CP surveillance system data, 1982-2014

Variable	Total in WARDA-CP (n) %	Not in IDEA system (n) %	In both surveillance systems n (%)
Total	582	81 (13.9%)	501 (86.1%)
Alive	470 (80.8%)	69 (85.2%)	401 (80.0%)
Deceased	112 (19.2%)	12 (14.8%)	100 (20.0 %)
Indigenous status			
Indigenous	80 (13.7%)	15 (18.5%)	65 (13.0%)
Non-Indigenous	502 (86.3%)	66 (81.5%)	436 (87.0%)
Sex			
Male	346 (59.5%)	49 (60.5%)	297 (59.3%)
Female	236 (40.5%)	32 (39.5%)	204 (40.7%)
Location			
Metropolitan	363 (62.4%)	52(64.2%)	311 (62.1%)
Inner and outer regional areas	95 (16.3%)	10 (12.3%)	85 (17.0%)
Remote and very remote areas	53 (9.1%)	6 (7.4%)	47 (9.4%)
Missing	71 (12.2%)	13 (16.0%)	58 (11.6%)

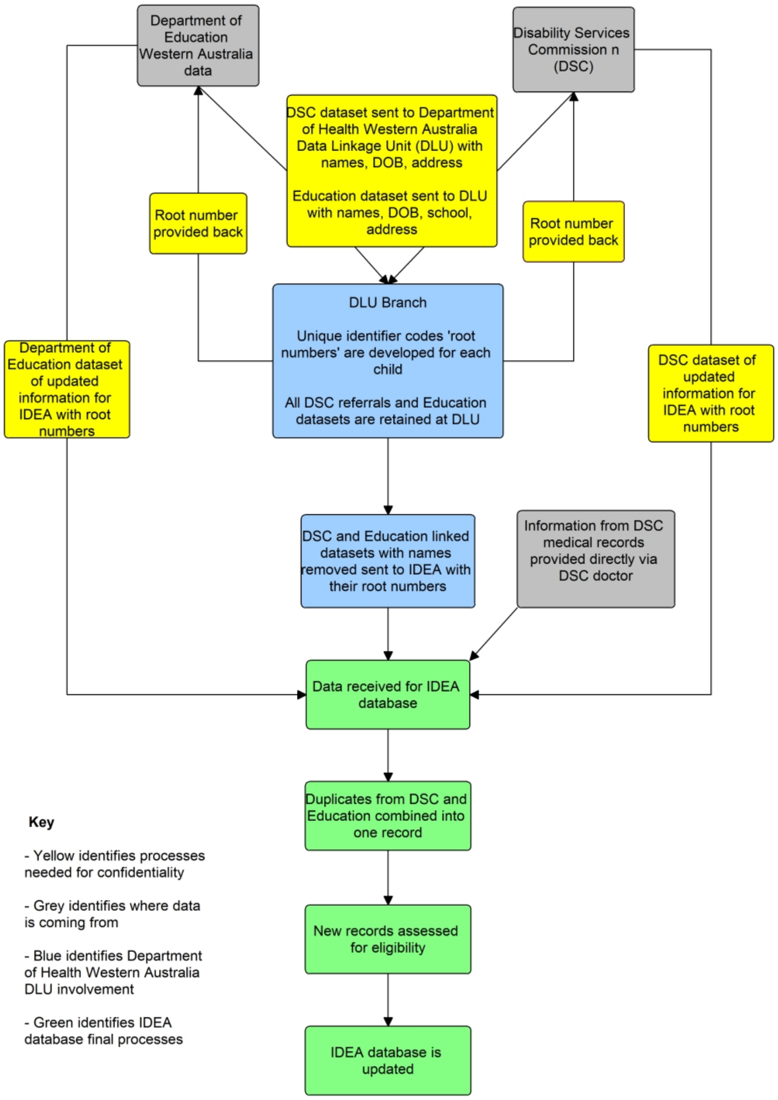
Box 1: Examples of policy and program relevant findings for people living with an intellectual disability

Antenatal care

- Improved management of women with diabetes, epilepsy and/or anaemia during the antenatal period to reduce the risk of having a child with intellectual disabilities.[38]
- Importance of monitoring maternal health due to poor fetal growth increasing the risk of intellectual disability.[36]
- Health promotion and public health campaigns to prevent the use of alcohol during pregnancy.[39]

Service delivery

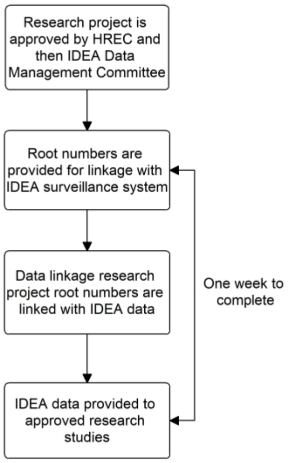
- Children with intellectual disability are also more likely to have birth defects resulting in increased health and social supports for children and additional services for families.[40]
- The need for additional services and support for families in areas of social disadvantage who are at greater risk of having child with intellectual disability.[36]
- Improved access, quality and coordination is needed for individuals with intellectual disability as they are more likely to experience potentially preventable conditions at the end of their lives.[35]



NOTE: The processes in yellow, grey and blue take approximately nine months to complete. The process outlined in green takes approximately four months to complete

Flow diagram of process of data collection for IDEA surveillance system

1166x1649mm (72 x 72 DPI)



Internal data linkage process for IDEA surveillance data

1166x1649mm (72 x 72 DPI)

Background of the IDEA system

The IDEA system originated from a dataset of individuals with intellectual disability receiving support from the Western Australian government, was established in 1953 and maintained by successive state governments performing this role. In 2002, the IDEA system was moved and currently is homed in the Telethon Kids Institute (Western Australia) and is a permanent population-based data linkage surveillance system.

Intellectual disability case definition

Disability Services Commission

A person is considered to be intellectually disabled if they have scored more than two standard deviations below the mean on a recent formal assessment of intellectual functioning (within the past 3 years); or scored more than two standard deviations below the mean on a recognised measure of adaptive functioning with demonstrated deficits in two or more of the following skill domains conceptual, social or practical; or if their clinical presentation is consistent with an intellectual disability. The onset of these conditions needs to have manifested prior to 18 years of age.[1]

Department of Education

Intellectual disability is determined through a diagnostic report which has had all components completed within six months and has considered factors such as language, cultural background, learning opportunities, disabilities, motivation and cooperation.[2] Determining intellectual disability includes an assessment of adaptive functioning using both clinical evaluation and standardised assessment with a significant impairment defined as two standard deviations below the mean on a standardised, culturally relevant assessment in at least one domain across multiple environments (e.g. home, school, community and work). Results and interpretations of assessments demonstrate a significant sub-average intellectual functioning of an intelligence quotient <70 on an individually administered appropriate IQ test; and evidence that academic achievement and progress is limited in comparison to age expectations.

Prior to 2006, confirmed cases from the Department of Education were included if the assigned level of ID was ‘mild or moderate’ or severe. In 2006, the level of ID provided by the Department was modified to represent the child’s educational level of need, rated from 1 (low need) to 5 (high need). In the absence of availability of information on ID level, cases with an educational need of 4-5 were considered to have an ID. An analysis of the correlation between the previously assigned level of ID and the level of educational need has shown that an EN score of 4 is correlated with a mild or moderate ID, and EN score of 5 with a severe ID.[3] In 2016 the level of educational need was replaced with an Individual Disability Allocation (IDA) which was rated from 1 (mild ID) to 7 (severe and comorbid ID) and used to estimate level of intellectual disability. Further enhancement of data is undertaken by a medical officer, located at DSC, using the four digit AAMR system to assign the most appropriate cause of ID to cases[4] which can be later grouped into broader categories. The onset of these conditions needs to have manifested prior to 18 years of age.

Supplementary Table 1: Data variables for IDEA surveillance system

Variable	Description
Unique ID	Unique identifier that can be used with other data linkage studies
Ascertainment source	Whether cases were ascertained through Department of Communities or Department of Education
IDEA eligibility	Described as Eligible, Eligible EDWA, Eligible Vulnerable, not eligible. 1. Note: “Eligible EDWA” are cases where there is insufficient information from Department of Communities to determine IDEA eligibility but sufficient information from Education is available. 2. “Eligible Vulnerable” are Department of Communities cases where level of ID is unknown but case has been deemed Vulnerable to ID.
ID level	Mild, mild or moderate, moderate, severe, unknown, Unknown but intellectually handicapped, borderline, Not intellectually handicapped
Sex	Male or Female
DOB Month	Month of birth
DOB Year	Year of birth
Client diagnosis	numeric Heber code for diagnosis – up to four can be recorded
Client diagnosis description	text description of diagnosis - up to four can be recorded
Autism Spectrum Disorder identified	Identifies clients with an autism spectrum disorder diagnosis
Cause of ID	Provides the broader group cause of ID if available. Described as biomedical, not medical – unknown, autism spectrum disorder with ID, insufficient information.

Note: ID (intellectual disability) and intellectual handicap are used interchangeably

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