

29 April 2011

Patricia Scott, Presiding Commissioner
John Walsh, Associate Commissioner
Productivity Commission on Disability Care and Support

By email: disability-support@pc.gov.au

Dear Commissioners,

Submission to Productivity Commission on Disability Care and Support Draft Inquiry Report

Summary

As the largest academic unit in Australia dedicated to research on personal injury insurance schemes we, the leaders of the Institute of Safety, Compensation and Recovery Research (ISCRR), commend Disability Care and Support, the Draft Inquiry Report by the Productivity Commission, as an appropriate way ahead to address the needs of a neglected group of Australians.

We are pleased to see in the recommendations a very clear commitment to the work of the proposed schemes being based on evidence and a capacity for research to provide it. Our comments in this submission focus on the proposals for data management and research.

Overall, we consider that there is scope to enhance the vision for research, described in the report, so that it will be more aligned with the literature on the utilisation of research in policy making and recent innovations in collaborative research.

We also see the potential for the research function associated with the proposed NDIA to be co-ordinated with existing and emerging research capacity in disability prevention and management (including compensation) to mutual advantage.

Our full submission is attached however, our key points are summarised below:

- **Options for how research would be undertaken** - Development of a research capacity which is independent, aligned to policy making needs and delivers high quality research is a mighty challenge which is easily underestimated. The research and policy making worlds are very different cultures. We have briefly described how ISCRR works as an example of an innovative, external research institute with close ties to the agencies and communities it serves, operating in the field of disability prevention and management, which shows promise.
- **Research capacity in NDIA** - While we agree that it will be important for the NDIA to have a research capacity, we also recommend that the NDIA explicitly focus on developing processes and capacity for the utilisation of research within its own organisation and within its community of interest, as well as developing the capacity for commissioning research.

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- **Data for research** - Research will be an important secondary use of NIDS and NIIS data. It will provide information that can be used to evaluate the efficiency and effectiveness of the schemes, as well as improving our knowledge of the impact of disability in our community and assist in identifying preventive opportunities. We recommend that likely users of scheme data be consulted during the design of data systems for both the NDIS and NIIS. Insights from research institutes such as ISCRR can assist with establishing data systems that will produce the highest quality research. Effective benchmarking will require a mix of quantitative and qualitative research methods and much can be learnt from international examples currently in operation.
- **Scope of the research** - We commend the commitment to evidence-based practice and the development of a research capacity to support this in the draft report. However, we consider that the utilisation of research is too narrowly described in the report. We suggest that the report reflect the potential for research to contribute to determining strategy, shaping programs, assessing stakeholder views to assist in driving cultural change as well as financial sustainability, the cost-effectiveness of service and interventions and performance measurement of service providers.
- **National co-ordination of research** - The federated approach to the NIIS represents a significant opportunity for developing a national personal injury compensation benchmarking scheme in Australia, as stated in the report. This is strongly supported.
- **Limitations of current personal injury compensation schemes** - Our concern is the assumption within the Commissions' report that Australian personal injury compensation schemes are operating 'well enough', when the research evidence suggests that they are in fact associated with poor health and work outcomes (that is, greater disability and poorer level of function) among those insured. Importantly these are system level problems that can be addressed by careful design of the NDIS and NIIS compensation schemes. We recommend that the research evidence in this area be carefully considered as the detailed design of the NDIS and NIIS is taking place.
- **Workplaces** - There is potential to undertake significant intervention research in the setting of workplaces to develop and test interventions which address occupational health and safety, health promotion, disability prevention and management in an integrated manner at the level of community (testing system cost effectiveness, not just efficacy at the level of individual workplaces).

ISCRR would be happy to provide further advice and assistance to the conceptual development of the research function if required.

Professor Niki Ellis

Chief Executive Officer

Alex Collie

Chief Research Officer

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Full submission

As the largest academic unit in Australia dedicated to research on personal injury insurance schemes ISCRR commends Disability Care and Support, the Draft Inquiry Report by the Productivity Commission as an appropriate way ahead to address the needs of a neglected group of Australians.

We are pleased to see in the recommendations a very clear commitment to the work of the proposed schemes being based on evidence, and a capacity for research to provide it. Our comments in this submission focus on the proposals for data management and research.

Overall we consider that there is scope to enhance the vision for research described in the report to be more aligned with the literature on the utilisation of research in policy making and recent innovations in collaborative research.

We also see the potential for the research function associated with the proposed NDIA to be co-ordinated with existing and emerging research capacity in disability prevention and management (including compensation) to mutual advantage.

Below we have commented on sections in the report which deal with research. In each case we have made a summary comment.

Options for how research would be undertaken – 10.5

We note the report considered four options for how research would be undertaken: develop an in-house capacity, commission from a variety of established organisations, fund the establishment of an external institute, and devolve responsibility to service providers to submit efficiency, effectiveness and economic assessments in their applications for funding.

We consider that our organisation provides an example of the external institute model which has been recently established, so far seems to be working very well, and is in this field.

ISCRR is a partnership between WorkSafe Victoria, the Transport Accident Commission and Monash University. It was established in April 2009 with the mission to conduct research aligned to scheme issues and objectives that will lead to fewer and less severe occupational injuries and diseases and improved health, vocational and social outcomes.

The motivation for its establishment was the desire:

- by the two personal injury insurance schemes to have a research capacity more aligned to their needs, specifically by ensuring research questions were directly relevant to policy problems, and that research outputs were timely and actionable
- by the university to model collaborative research processes which had a significant focus on community impact, a future direction for academia, and a major focus of this university's corporate strategy.

The business model for the collaborative research organisation developed by ISCRR is shown below.

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Features of the collaborative research model are:

- significant attention to setting the research agenda and translation of the research, as well as doing the research
- high priority given to stakeholder engagement. In fact the objective for stakeholder engagement is 'Maximise the potential impact of our research by optimising our engagement with stakeholders in setting the research agenda, conducting research and translating research into policy and practice'.

The corporate structure of ISCRR is an innovative one developed by Monash University for the establishment of its Sustainability Institute. In this model the research organisation is not an incorporated entity, rather it is a partnership, for example, ISCRR is a partnership between the two Victorian personal injury schemes and the university. The research organisation is administered through the university. By and large, it follows university policy and procedures. However, the Vice Chancellor has devolved his responsibilities to the ISCRR Board which is comprised of six representatives from the three partners and one independent representative. Therefore, it is fairly easy to be innovative and go beyond current university systems.

Funds have been provided for research in a five year contract but research plans are approved by the two regulators. Each research project plan is approved by the ISCRR Board thus the regulators have significant control of the research which is undertaken. However, as the organisation is administered by a university, there is good quality control, for example via ethics committees, the university review process and the academic culture of peer review. In addition, there is a significant degree of independence in the way the research is conducted and the publication and translation of the research.

Summary – Development of a research capacity which is aligned to policy making needs, independent, and delivers high quality research is a mighty challenge which is easily underestimated. The research and policy making worlds are very different cultures. We have briefly described how ISCRR works as an example of an innovative model of an external institute with close ties to the agencies and communities it serves, operating in the field of disability prevention and management, which shows promise.

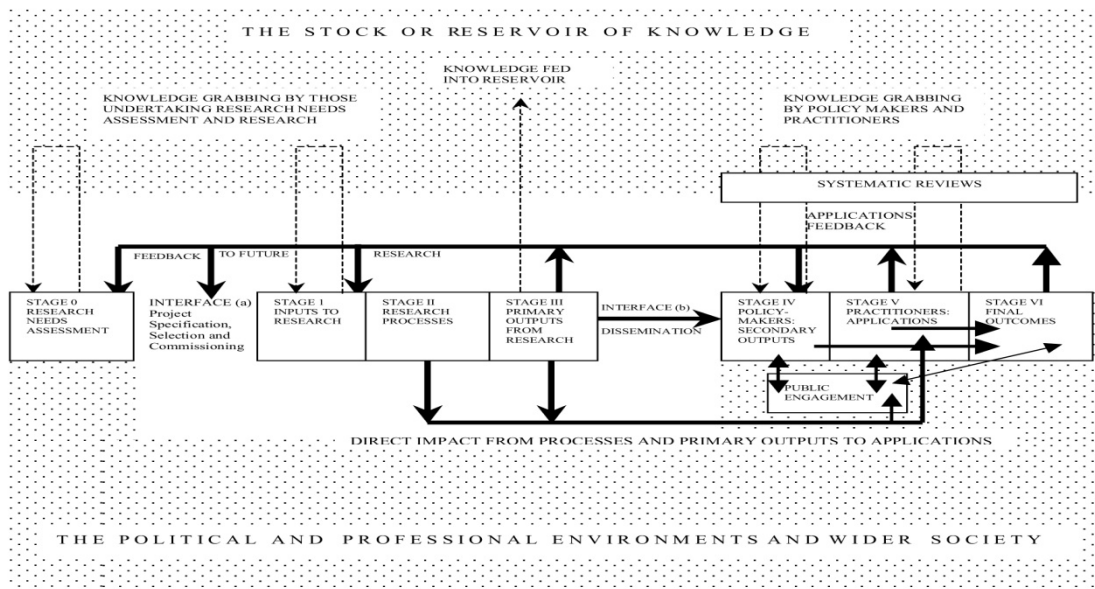
Research capacity in NDIA

We note the functions of the NDIA include a research function. There is a growing body of expertise regarding effective models of evidence translation between policy organisations and research groups. This is a focus of ISCRR's research program and is embedded in our operational interactions with our partner organisations.

The field of research or evidence translation has evolved since the 1960s through three major phases:

- 1st generation was practised from 1960s-1990s. This was a one way process, undertaken on completion of research which involved the academic or research sector 'pushing' information towards practitioners and policy makers. It was not considered effective but important lessons were learnt.
- 2nd generation emerged in the mid-1990s and is most active now. This has been described as the 'two communities approach', and focuses on interactions between researchers and policy makers, or the exchange of information.
- 3rd generation is only just emerging now. In this generation there is recognition of the need for receptiveness and a capacity by the policy making organisation for research. This can be categorised as increasing the receptiveness and the 'pull' of the policy maker while improving the relevance of the information being produced by researchers.

Shown below is a model of the use and generation of knowledge in the process of research, and the utilisation of research in policy and practice which we have found helpful¹.



¹ Hanney et al, 2003, The utilisation of health research in policy-making: concepts and examples and methods of assessment. <http://www.health-policy-systems.com/content/1/1/2>

Summary – While we agree that it will be important for the NDIA to have a research capacity, we also recommend that the NDIA explicitly focus on developing processes and capacity for the utilisation of research, within its own organisation, and within its community of interest, as well as developing the capacity for commissioning research.

Data for research

Compensation systems are a potentially very important source of research data. While the primary purpose of such data will always be to manage the compensation scheme, an important and very valuable secondary purpose is to use the data for research. Such data can provide highly valuable information regarding the impact of disability on the individual, their community and society as well as assist with identifying and targeting preventive initiatives.

Internationally, there are numerous examples of disability compensation schemes making their claims and administrative data available to academic researchers. For example, in British Columbia, Canada the WorkSafe BC claims data is linked to population health data via the unique Population Data BC collaboration based at the University of British Columbia. This data has been used to evaluate the effectiveness of programs initiated by the workers' compensation organisation and the public health system within that jurisdiction. Similarly, the Workplace Safety and Insurance Board of Ontario regularly provides its data to researchers. Within Australia, ISCRR has recently established a research database using TAC and WorkSafe claims and administrative data.

Data requirements for research purposes are not always aligned with data requirements for claims management and scheme administration. Issues of quality control, coding systems, data continuity, training of those entering data and many others must be addressed if the data is to be most effectively used for research purposes. The ability to link data with data from other systems, e.g. the healthcare systems, provides a very powerful additional tool that can substantially enhance the value of scheme data.

We also note the reference in the federated NIIS to benchmarking between jurisdictions. This is clearly of value and there are a number of well-established international examples, most notably in the USA via the Workers' Compensation Research Institute. Methods used elsewhere include a combination of quantitative and qualitative research methods. This usually involves identification of issues via quantitative benchmarking using claims data and then detailed qualitative investigation of the issues using other techniques such as industrial ethnography.

Summary – Research will be an important secondary use of NIDS and NIIS data. It will provide information that can be used to evaluate the efficiency and effectiveness of the schemes, as well as improving our knowledge of the impact of disability in our community, and identifying preventive opportunities. We recommend that likely users of scheme data be consulted during the design of data systems for both the NDIS and NIIS. Insights from research institutes such as ISCRR can assist with establishing data systems that will produce the highest quality research. Effective benchmarking will require a mix of quantitative and qualitative research methods and much can be learnt from international examples currently in operation.

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Scope of the research

At a seminar held at La Trobe on 12 April to discuss the report, the campaign manager of the National Disability and Carer Alliance, John Della Bosca, emphasised the importance of the work of the proposed NDIA in the reform of society to remove the many barriers which currently exist for people with disabilities living and working in our communities. The proposed schemes will interface with a great variety of existing personal injury compensation mechanisms, providers of health and disability services, and organisations in housing, employment, education and welfare. This is recognised in the report, for example in figure 2 on page 32. These functions are the 'upstreamed' functions which promise significant benefits, but in the longer term, and are included in tier 1 of the NDIS.

The services proposed in tier 2 of the NDIS are truly innovative and could be seen as a model for consumer-centred health care often discussed in health care reform. As it stands the report describes this function as provision of information and referral to appropriate services. Assisting people with information on complex service delivery systems is important, but what is really needed is support for people who are eligible for tier 2 services to manage their problems themselves. There is a growing evidence-base for self-management in the field of chronic illness, and now this is being picked up in the field of vocational rehabilitation, where there is increasing recognition that improving the self-efficacy of people with a disabilities to navigate the compensation system and achieve return to work is an intervention point of potential benefit, to complement interventions to create supportive environments in workplaces. It is recommended that the philosophy of the services in tier 2 be drawn from self-management to improve health literacy and self-efficacy, which goes beyond provision of information and referral.

From a review of the literature on research translation we have derived three purposes policy makers have for research:

- Tactical research generates knowledge which can be fed immediately into decision-making, eg comparison of the cost-effectiveness of different services and interventions
- Strategic research generates knowledge which can be used to provide conceptual frameworks for considering emerging issues or options for policy.
- Symbolic – Symbolic research is when a policy maker wants a credible source of research to justify a policy position.

The report as it focuses on tactical research based on quantitative data, specifically:

- Facilitating financial sustainability
- Ensuring cost-effective services and interventions
- Monitoring the performance of service providers.

Given the significant unmet immediate needs of people with disabilities it will be easy for the young NDIS to be overwhelmed by the demands of tier 3. Strategic research, such as foresight research, modelling of benefits, systems research, as well as the tactical research proposed in the report currently would help to create a futures-focussed evidence-based strategy for the NDIS.

Early in ISCRR's relationship with its industry partners we found they considered their needs for research tended to be limited to outcome evaluation (had a program worked or not), or research to help them to determine options for a well-recognised problem. As we have worked together a much broader range of opportunities to provide research into the scheme processes has been developed including:

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- Foresight research to identify emerging issues to inform business planning
- Attitudinal research to inform schemes on stakeholder views (eg as done by sociologists or anthropologists or industrial ethnographers – more in-depth than the market research already commissioned by the schemes)
- Evidence synthesis on possible interventions to inform decisions about whether interventions are advisable, and if so what works
- Action research to inform the development of programs, formative evaluations
- Identification/development of reliable and valid indicators for use by the schemes
- Evaluation (summative).

What is very clear from centres of excellence in collaborative research is that the synthesis of existing knowledge, as well as generating new knowledge, is an important component. At ISCRR our most frequent request is for rapid reviews.

Summary – We commend the commitment to evidence-based practice and the development of a research capacity to support this in the draft report. However we consider that the utilisation of research is too narrowly described in the report and suggest that the report reflect the potential for research to contribute to determining strategy, shaping programs, assessing stakeholder views to assist in driving cultural change as well as financial sustainability, cost-effectiveness of service and interventions and performance measurement of service providers.

National co-ordination of research

The field of disability prevention and management research in Australia is very small. There is potential, and we believe, value in developing a nationally co-ordinated approach to research in this area. The advantages of this are:

- Facilitation of benchmarking – an important methodology for research on the efficiency and effectiveness of schemes
- People with catastrophic injuries are relatively small in number; co-ordination of research will prevent them from being overwhelmed by requests to participate in research
- Researchers with expertise in this area are relatively few and coordination would provide a way of ensuring the best outcomes from this small group of expertise.
- Encourage learning from sub-sector to sub-sector.

National co-ordination of workers compensation and motor accident compensation research is at an early stage. For example ISCRR in partnership with the Accident Compensation Commission in New Zealand will be holding the inaugural Australasian Compensation Health Research Forum in October this year.

Summary – The federated approach to the NIIS represents a significant opportunity for developing a national personal injury compensation benchmarking scheme in Australia, as stated in the report. This is strongly supported.

Limitations of compensation schemes

That the proposed NIIS is built around the existing schemes for workers compensation and existing no-fault motor accident compensation schemes implies that these schemes are working well enough. However within the field of personal injury compensation research there are concerns that aspects of the compensation schemes may be leading to poor health and work outcomes for those with compensable injury.

There is now substantial evidence that people who receive compensation have worse health and well-being than people with equivalent afflictions who do not receive compensation. 'Compensable' clients are slower to return to work, have poorer self-reported physical and mental health and use more health services than 'non-compensable' clients. They are also more likely to be hospitalised and more likely to undergo surgery.

This so-called 'compensation effect' appears to operate across state and national borders and is not specific to any individual compensation system. There is a long list of possible causes for this effect, and these generally fit in one of two broad theories. The 'secondary gain' theory proposes that being involved in compensation process creates an unconscious incentive for the injured person to remain unwell. In contrast, the 'secondary victimisation' theory proposes that being involved in the compensation process is complex and stressful, and that it gives rise to renewed victimisation for the injured person. A close inspection of most Australian personal injury compensation systems reveals many examples of these theories in operation.

Summary – Our concern is the assumption within the Commissions' report that Australian personal injury compensation schemes are operating 'well enough', when the research evidence suggests that they are in fact associated with poor health and work outcomes (ie, greater disability and poorer level of function) among those insured. Importantly these are system level problems that can be addressed by careful design of the NDIS and NIIS compensation schemes.² We recommend that the research evidence in this area be carefully considered as the detailed design of the NDIS and NIIS is taking place.

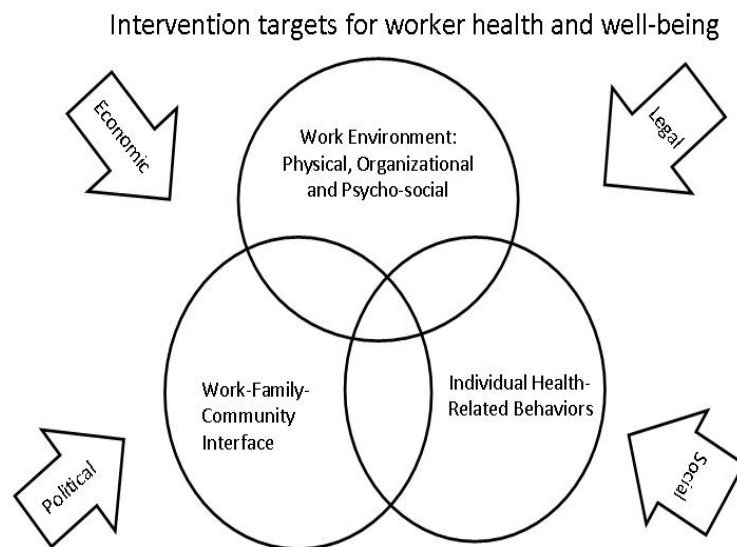
Workplaces

Although there are many 'settings' which will be important to the work of the NDIA, eg housing, education etc, workplaces are shaping to be particularly important. Skills shortages means that workplaces may be receptive to change to better accommodate people with disabilities, and there is relatively recent recognition that work is good for your health. As well industry is increasingly sensitive to social responsibility. However there is a lot already going on in workplaces: occupational health and safety is increasingly interested in action by employers to improve return to work rates after work-related injury and disease; motor accident compensation authorities are also ramping up return to work initiatives; and the health sector sees workplaces as an important setting for health promotion. New models are emerging in which occupational health and safety and workplace health promotion are integrated. Recently the

² A. Collie & N. Ellis, Letters to MJA, 4 March 2010

National Institutes of Health and the Centre for Disease Control in the US ran a workshop which resulted in a new evidence-based model, shown below³.

The explicit link to community and family is an interesting addition to earlier integrated (occupational health and safety and workplace health promotion) models and can be useful in co-ordinating engagement with workplaces on the health and disability agendas.



Summary – There is potential to undertake significant intervention research in the setting of workplaces to develop and test interventions which address occupational health and safety, health promotion, disability prevention and management in an integrated manner, at the level of community (testing system cost effectiveness, not just efficacy at the level of individual workplaces).

³ Sorensen, G, Landsbergis, P, Hammer, L, Amick, B, Linnan, L, Yancey, A, Welch, L, Goetzel, R, Flannery, K, & Pratt, C, "Preventing Chronic Disease At the Workplace: A Workshop Report and Recommendations", *American Journal of Public Health*; <http://centerforworkhealth.sph.harvard.edu/index.php/publications/manuscripts> – in press