

The Impact of Public Policy on Support Services for Indigenous Families with Children with Special Education Needs

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In Australia and Europe, government agencies and not-for-profit organisations (NFPOs) have had long involvement in the funding and provision of community disability services. Significant change has occurred in Australia over the past two decades in the way government funds are expended, with marketplace mechanisms increasingly being used. As a consequence of economic and governance imperatives, funding of services via NFPOs has changed significantly with a move away from the provision of grants to the contracting of these organisations for the provision of services. In 2013, a new national policy, the National Disability Insurance Scheme (NDIS), was introduced that has impacts for the provision of disability services for children and their families. In particular, Indigenous families are likely to experience barriers in accessing services. This paper reviews the impact of international changes in policy and associated funding models and considers the impacts and research implications of Australia's initial experience of implementation of the NDIS.

■ **Keywords:** culturally appropriate, disability, funding, Indigenous, not-for-profit organisation, service provision

International Disability Policy

Policy positions internationally have moved to incorporate rights for persons, including children, with a disability. Many countries have become signatories to a range of conventions and agreements that enshrine these in the constitution or legislation of these respective countries. These are usually based on the United Nations Convention of the Rights of People with Disabilities (UNCRPD) (United Nations, 2006). Since March 2007, Australia has also been signatory to this agreement (United Nations, 2014). However, Smyth et al. (2014) point out that shared intent through agreement to international conventions with common legislative or provisional outcomes cannot mean that equivalence of provisions, practices or outcomes can be assumed. Enabling legislation, funding mechanisms and the implementation of policies has varied significantly across countries impacting on access, participation and levels of service provision. Even within individual country jurisdictions, differing legislative definitions, placement of authority and decision-making to national, state or province, or local government, and models of funding and its disbursement through these authorities, impacts on effectiveness of services delivered. Goldthorpe

(2004) emphasises the need for legislation related to disability, special education, mental health, and child care standards to be coordinated to ensure that tribunals, local authorities and provider institutions are not characterised by tensions and obstacles but can share information and assessments to better meet the needs of individuals.

In the United Kingdom, the Every Child Matters policy and legislation has been implemented in response to the United Nations agreement on the Convention on the Rights of the Child (Children Act, 2004; Department for Education and Skills, 2004). This legislation, and associated policies, sets out a national framework around the needs of children and young people. A key focus of the Act was the creation of partnerships between local agencies providing education, health and social care, including disability services (Reid, 2005; Percy-Smith, 2006). Pilot programs commenced in 2002/03 as Pathfinder Children's Trusts (Mahoney, 2006). Mahoney highlights

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fundamental principles of success for their project as requiring early intervention, and for staff of institutions involved to have regular contact with families and to become familiar with family circumstances, to build trusting relationships. These principles were essential to 'break the cycle of accumulative disadvantage' especially for the most needy children (Mahoney, 2006, p.51). Review of services and service providers has also noted the importance of using the voices of children and their families to empower them to influence the development of policy and to increase their autonomy in accessing services (Aubrey & Dahl, 2006). Though it is clear that the manner in which this is done must be genuine and authentic. Kelley (2006) warns against exploitative or tokenistic processes that do not involve participation in an open process of knowledge formation between policy makers and those in receipt of services.

European Policy

Similar changes in disability services are happening across Europe with most member states being signatories to the European Disability Strategy (European Disability Strategy, 2010–2020) adopted by the European Commission in 2010. The strategy builds on the UNCRPD and strengthens the European Action Plan (2004–2010). Under the European Action Plan (2004–2010) funding is provided to member states through the European Social Fund which includes accountability and compliance requirements with agreed regulations. While funds are provided through the central fund, there is a range of funding and service provision models within member states that meet the compliance requirements. For example, the United Kingdom has a tradition of Independent Funding of Services (Leece & Leece, 2006) but other areas of Europe have place-related funding systems of specialised assistance services.

Member states are also responsible for innovating national policies to meet shared Open Methods of Coordination (OMC) (Priestley, 2014) and there have been a range of funding and service provision models developed (Weinbach, 2004). Development of inclusive learning environments, in the four European countries included in the Smyth et al. (2014) study, was impacted by supporting legislation, inclusion policies and budgetary models. As a consequence, there still remain serious concerns about the adequacy of support given the impact of market economies and budgetary constraints (Kramann & Biewer, 2014; Smyth et al., 2014). Similar to Australia, the involvement of NFPOs is strongly recommended as the member states do not want to be involved in direct service delivery (Priestley, 2014).

Background to the Funding of Disability Services in Australia

In Australia, NFPOs have long been involved in funding and provision of community disability services. This his-

tory of involvement began in the 1800s when voluntary organisations, often church related, funded by donations from philanthropic citizens provided services to persons in need. In 1974, when the Australian government commenced funding of disability services these same organisations continued to provide the services under similar models of service provision that they had been using previously. The grants model of funding to NFPOs continued through to the 1990s, when as a consequence of economic and governance imperatives, funding of services via NFPOs moved to contracts for services.

The move to contracting for services had three significant impacts on the provision of services through NFPOs. First, it moved control of identification of specific services to be offered and eligibility of recipients to the contracting authority. Tenders for contracts included statements outlining what services would be offered, to whom and under what conditions. Second, the contracts required an increased level of accountability for both funds and service objectives as stated in the contract. These accountability measures necessitated a portion of funding to be rerouted into administration in order to meet the reporting requirements. The focus on accountability has also had significant impact in the delivery of social policy initiatives including disability services in countries throughout the European Union (Smyth et al., 2014; van Zanten, 2014).

Third, the changes impacted on the locations where services were provided. The increased emphasis on market place mechanisms meant that NFPOs needed to be competitive in responding to tenders. In the geographical landscape of Australia where many families requiring services live in rural and remote locations, it is significantly more expensive to provide services in many communities.

Australian Policy Developments

In Australia there have been recent policy developments with the introduction of a range of legislative changes impacting on the disability sector. The National Disability Strategy (2010–2020) is a ten year national policy framework that sets out six priority areas for action to improve the lives of people with disability, their families and carers. These include inclusive and accessible communities, rights protection, justice and legislation, economic security, personal and community support, learning and skills and health and wellbeing. The strategy will guide public policy across all state governments and aims to bring about change in all mainstream services and programs as well as community infrastructure. It is the first time the Commonwealth, State and Territory governments in Australia have agreed to such a wide ranging set of directions for disability.

The need for an agreed national definition of disability and a better way of understanding the nature of educational adjustments has been recognised in Australia

for some years. The Review of Funding for Schooling (Gonski, 2011) commonly referred to as the Gonski Review found that the lack of consistency and quality of data about students with disability in Australia across education systems was a significant barrier to recommending a funding loading. The review recommended that jurisdictions collaborate to collect national data and agree on a consistent definition of 'disability' that could be used in the funding model.

To address these concerns the Nationally Consistent Collection of Data on School Students with Disability (Department of Education, 2014) was undertaken to inform the development of the disability loading. The model which was developed does not use the traditional diagnostic approach to disability, instead taking a functional approach by seeking data on the level of adjustment required by students. An evaluation report (PricewaterhouseCoopers (2013)) found that the model was robust enough to proceed to full implementation in 2015. However, some major risks and challenges were identified that needed to be addressed. There were significant gaps in awareness of disability and adjustment throughout all school systems so targeted training and preparation through detailed preparation for the data collection was required. A major problem that was identified related to the data collection model requiring teachers with little or no training and experience in inclusive education to make sophisticated judgments about the level and types of adjustments students may require.

However, although there were concerns about the accuracy of the data, the report confirmed the direct experience, of students with disability and their families, of a system which has chronically failed to provide crucial educational adjustments. The trial report of the NCCD estimates that the number of students with disability is a minimum 8.4% of the population but only 5% receive funded support (Productivity Commission, 2014). Therefore, although Australia has now an agreed upon data collection method, there is no agreed strategy about how to use or analyse the data or how it will be used to guide the design and implementation of the loading, or what specific outcomes it will achieve in education systems. This situation is exacerbated by the Australian Government's delay in implementing all of the funding recommendations of the Gonski Review (Gonski, 2011; Graham, Proctor, & Dixon, 2016).

In 2013, the National government introduced the National Disability Insurance Scheme (NDIS) which is providing funding for the provision of services for persons with disabilities and their families. This policy has been introduced to provide choice, control and community participation. Persons with disability, their families and carers have a choice of services to meet their individual needs. They are given control of the funding and this support can be lifelong, but will be aimed at supporting integration and participation in the normal community

and the use of mainstream services. It was originally not intended to take the place of age 6–16 education or health funding; however, it is now becoming obvious that there is a need for interface between the education systems and the NDIS. The funding is generous in comparison to previous schemes in Australia and its premise is to increase independence and acceptance. However, the mechanism for dissemination of the funds has significantly changed.

Under the scheme there will be different levels of support called Tiers. Tier one targets everyone in Australia. Funding allocated at this level is to be used to create general community awareness about the issues faced by people with disability and promote inclusion and opportunities for people with disabilities. Tier two targets people with disability and their family and carers and provides general information about the most effective care and support options within generic and community support groups and services. Tier three targets people who need specialised supports, aids and equipment from specialised and/or generic services and facilities in the community, and importantly the development and funding of a personal support plan. Tier three is the level of most interest to the majority of people with disabilities and is the level of interest to this paper. Although there is support for this and similar models (Duff, 2014) in the grey literature there is very limited support in the research literature.

The NDIS is currently being trialled in a range of different locations in Australia. There are currently many trial sites across different states and territories. These sites include a wide range of geographical areas. For example, the Northern Territory site covers a large land area of over 323,514 square kilometres and includes remote Aboriginal communities. At this stage the National Disability Insurance Agency (NDIA) is promoting awareness and knowledge of the NDIS in trial communities in the Barkly region. All states and territories now have detailed individual roll out plans and at the present time it is planned to have complete coverage of all states and territories by the end of 2018 except for Tasmania which will have a full roll-out in July 2019.

The particular group that may be vulnerable under the NDIS is Indigenous Australians particularly those who live in rural and remote regions. The under- or non-reporting of disability is frequent within Indigenous communities. Some Indigenous Australians find the concept of disability hard to understand or irrelevant reducing the likelihood of reporting of living with a disability. In some Indigenous languages there is no term for disability. Culturally, this may suggest disability may be accepted as part of the human experience or as a unique attribute of the individual. Equally, Aboriginal people with disability are often reluctant to take on the label of disability if they have experienced discrimination based on their Aboriginality or have had experiences as members of the 'Stolen Generation' (First Peoples Disability Network, 2013).

Potential Impacts of Change of Policy for Persons with Disability

It is common for children with disabilities in Australia to receive support from educational, respite, therapy and specialist medical services. Access to these services in rural and remote areas of Australia has long been acknowledged as a problem for families of children with a disability (Aging, Disability and Home Care, 2012).

The Experience of One Not-For-Profit Organisation

A school readiness program for Aboriginal children with additional needs was conducted by Northcott, a NFPO in New South Wales (NSW), in two sites in NSW, one urban and rural. A study of this program found that parents had received limited information about disability and many found it difficult to identify their child's support needs (Purcal et al., 2013). The resources that had been provided were not sufficient to inform them about what services were available, what their rights were and how to access the services. This finding is not surprising given previous research that has found that dominant culture services and information may be very ineffective for people in remote communities (Sutherland & Billimoria, 2011; Constable, Dixon, & Dixon, 2013).

It has been found that Indigenous children with disabilities are more likely to be identified through the local education system than through the medical system particularly for children at risk of mild intellectual disability (Leonard, Petterson, Bower, & Sanders, 2003) because of lack of knowledge and lack of willingness to attend intervention services. Unless Aboriginal families can be given this information in a culturally sensitive and appropriate way they may have great difficulty in identifying their child's disability and therefore being able to act as an advocate for that child which is expected under the NDIS. Purcal et al. (2013) did find that in both communities many parents found it difficult to identify their child's support needs. In both communities, it took several weeks for the workers to build up a trusting relationship with parents that enabled them to discuss their child's needs. Although the intervention was successful, different research methodologies were needed to make for both a successful research project and intervention. The most important strategy was the development of trusting relationships between the dominant culture, staff and the families of the children. This is consistent with the findings by Mahoney (2006) in the United Kingdom. The findings were related to both rural and urban sites but were more significant in the rural setting.

The history of the impacts of policy change both in Australia and Europe, and the extant literature including the results of the Northcott program indicate potential implications on the provision of services by NFPOs

and on the awareness of, access to and utilisation of services by some groups of clients. It is likely that Aboriginal families with a child with a disability, particularly those living in rural or remote communities, the thrice disadvantaged group, will have difficulties utilising the NDIS model.

The Australian National Disability Insurance Scheme

The NDIS is an insurance based model where individuals need to approach the NDIA themselves before they can be considered to receive services. As yet there is no provision for families who have not self-identified to be linked to services. There is also no provision for case management. Once the family has self-identified an individual plan and budget is developed by administration staff 'planners' that is 'reasonable, effective, necessary and beneficial' (NDIA, 2014a). It is a, 'tell me what you need and how can I deliver it to you for you and your community', approach. The problem that has already arisen is that the planners have limited experience and expertise in the field of the provision of early intervention services and limited understanding of culturally and linguistically diverse families (Taylor, 2014).

The funding is vested in clients and families, and service providers are already aware that they will need to treat and relate to their clients in a different manner as the funding is 'portable'. Families can literally 'shop around'. Families can choose the services they want and instead of justifying their choices to the government, services have to attract clients and provide them with the services they choose. There is also a very limited discretionary funding for the services to support families through the identification process or through the time period where in the past families have been nurtured through the diagnostic process that can take up to 6–12 months.

To qualify for services the young child and their family needs to have a permanent disability which impacts on their capacity to participate in the community. This requirement has already caused difficulties in the trial site in Victoria and it has now been acknowledged that a specific diagnostic label may not be attached to each child. Already there has been a shift by the NDIA to accept the more general diagnosis of developmental delay, so that the need for a specific diagnosis has been softened. However, there has also been recognition that a diagnosis may be hard to achieve before the age of six. As seen in Europe, intervention needs to be implemented as early as possible. This will be a continuing area of contention because of developmental changes in children of this age.

The capacity to access appropriate services from remote locations is another potential issue. It has to be acknowledged that it is already difficult for families who are thrice disadvantaged to access specialist services that are necessary for attaining a diagnosis. The need for assistance with

accessing services for families with young children with disabilities who live in rural and remote areas has been recently recognised by the Better Start for Children with Disability initiative (2014). Under this initiative families can claim a one off payment of \$2000 to aid travel expenses in gaining a diagnosis. After a diagnosis has been given, then families may claim up to \$6000 a year to help with accessing therapy services. However, these funds are only available for a list of defined disabilities which are unlikely to be diagnosable at an early age.

Potential Impacts of Change of Policy for Service Delivery

The change in funding model is likely to impact on the models of service provision as competitive market forces influence availability of service options by NFPOs. The existing services that have been reliant on a steady and reliable stream of government funding will sink or swim in the newly created market. The NFPO providers may have to compete with the for profit providers who may not provide services for the Tier 3 families because they may not be cost effective. Market place forces may mean that hard to service clients may not be attractive from an economic perspective. Service providers will potentially view families as their customers and vie with each other for the funding dollars allocated to families.

Services will have to rethink, part, or possibly all, of their business model. Under this model, there is no guarantee of income, funding for a service is on a fee for service basis. Disability services need to make decisions about which services they will provide, how they will provide them and at what price and to whom. Instead of handling a few government contracts they may need to handle potentially hundreds or thousands of individual contracts. This change will have an impact on technology, infrastructure, staffing and services. There may be large changes such as payment for performance, the emergence of multiple sector partnerships and the need to secure funding outside of the NFP sector. For example, there will be no funds allocated for client or case management.

There is potential for NFPOs to be pushed out of the market in the disability services sector as for profit organisations become more active in the sector (Duff, 2014; Stubbs personal communication, 2014). Large for profit agencies may come to dominate this market as they have existing business models and the economic capacity to modify their budgets and employ professional administrative staff to facilitate the marketing and financial requirements necessary to survive in this funding environment. However, with limited funding and limited financial expertise smaller service providers will experience significantly greater impact. This may force existing smaller NFPOs to form partnerships or amalgamate in order to remain competitive.

Potential Impacts on Schools

A new area of implementation of the NDIS has commenced recently. It has been acknowledged by the NDIA that extra supports are needed by students enrolled in schools in the 16 to 18 years age range. Traditionally services for these students were funded by the relevant state departments of education. However, under the NDIS there has been recognition of the need for nonlearning related supports that have not usually attracted education funding. The interface between the NDIS and schools will impact on existing, and require the development of new systems, networks and responses (NDIA, 2014c).

The NDIS at the moment is funding some additional supports to encourage enrolment and attendance at schools. They are encouraging learning through funding of aids, computers, text books and other necessary equipment. They will also fund adjustments to buildings and adjustments to the curriculum to encourage enrolment in inclusive environments. Provision of day to day personal care and supervision for behavioural issues may also be supported by funding as a way to maintain inclusive enrolment. There needs to be awareness that there will be service gaps in rural and remote areas that are well known as difficult to service. There may be a need to monitor coverage and undertake market development to attract providers. Infrastructure demands which are difficult to support by individualised budgets and cost effective solutions will be problematic. Targeted block funding may need to be reintroduced to allow these types of additional supports in remote areas.

This is a very new area in the literature, and presently there is minimal research evidence or literature on this topic, particularly as it relates to rural, remote and Indigenous contexts. There is also a limited knowledge about how the two systems, the NDIS and the education system, are going to collaborate to provide services. For example, at the Barwon trial site in Victoria there was difficulty in the systematic connections as joint processes were not delineated and the NDIA planners demonstrated a lack of knowledge of school processes. This resulted in parents having to submit individual service plans to the NDIA planners without any input from the child's teacher or principal who best knew the child and their needs. This lack of connection to the holistic needs of the child has required the NDIA to implement a new model which includes a children's directorate with specialised teams that can liaise with the education sector and families (McDonald & O'Callaghan, 2015).

At the present time the interface between the NDIS and the education departments in each state is very fluid in that it is confusing, inconsistent and subject to ongoing change. However, there are some areas that have emerged that clearly need attention. Clarity and consistency are required in the linkage between the two systems. This will avoid anomalies such as the Albury/Wodonga problem

where two towns situated close together, divided only by the Murray River, are experiencing differential funding as they are in separate states (McDonald & O'Callaghan, 2015). Effective collaboration more broadly, between these two systems and other stakeholders including families, teachers, therapists, support personnel, communities and NFPO's delivering services is urgently needed to provide the most efficient and effective provision of services. The inclusion of schools in the NDIS process is an important development, but there are still a range of problem areas that need addressing.

Requirements for Future

With the potential of significant impact on both service providers and services accessed, it is timely for research to be conducted to investigate whether there will be impacts on the provision of disability services for children and their families across rural and remote regions. Research should particularly focus on the impact of changes in policy and associated funding models on families of Indigenous children with disabilities. It should consider levels of awareness, access and utilisation, and issues experienced with 'dominant culture' services provided, and the nature of the organisations delivering the services. There is a need for research that is culturally sensitive so that organisations can provide more accessible service models for Indigenous families who have children with disabilities. Under the new policy, people with disability who may have the most complex needs, the most high-support needs or even challenging, aggressive behaviours may be disadvantaged if a market is not created that encourages organisations to offer services to meet their needs.

Researchers need to establish relationships within communities, gain knowledge of the dominant family groups and build trust with families. Researchers should become known to the families and communities before commencing research projects. If possible the researchers, project manager and research assistants should attend community days, fair days and perhaps sporting events. Only after these initial contacts have been made and relationships formed should there be contact with schools, parenting groups and local Aboriginal Education Consultative Groups. It is also useful to gain knowledge of the dominant family groups in the community, preferred names and language groups. Culturally appropriate methodologies that have been used successfully include: needs analysis conducted with family groups and community; semistructured focus groups and interviews with families, Elders and other key community members. These methods allow for the exploration of motivations, knowledge of issues, knowledge of solutions, and access to solutions.

As with the European findings for sensitive and authentic development of shared knowledge (Aubrey & Dahl, 2006; Kelley, 2006) it is important in this phase of the research to listen to the voices of families and communi-

ties and to build capacity to empower and support families and communities. Indigenous researchers also emphasise the need to include Indigenous perspectives and to identify culturally appropriate, community engaging approaches (Trimmer, Dixon, & Stubbs, 2014). The final phase of any research should involve reciprocity by feeding back to communities the results of any research in a form that is acceptable to all of the contributing communities. This can then be used by the communities such as the Yarn-up sheets developed as part of Positive Partnerships and First People Disability Networks recent awareness raising program in Aboriginal and Torres Strait Islander communities (Casuscelli & Riemer, 2016). There are four expected outcomes: knowledge transfer to enable awareness of services available; capability for enable families to identify the needs of their children and their preferred services; capacity building of families to act as advocates in accessing services to meet these identified needs; and to be empowered to utilise the services effectively.

Conclusions

If the development of services can be based on the findings of culturally relevant research, then these services have the potential to improve relationships and communication between service providers and Indigenous families of the child with a disability. More widely, the support programs that the families utilise can potentially impact on social determinants of disability by improving engagement, employment and empowerment if implemented in a culturally appropriate manner and provide much needed information for all of these stakeholders to increase awareness and understanding about services and about Indigenous families with a child with a disability. The development of culturally appropriate services can inform policy, specifically in the areas of medical therapy educational and social support services. Culturally competent advocates and planners will need to be provided to ensure that Indigenous families are empowered to make informed choices and be able to maximise benefits for their children under the NDIS. Consistent with Goldthorpe's (2004) recommendations, there is a continuing need for all aspects of services and provider institutions to share information, assessments and diagnoses to provide cohesive personal support plans for each individual to avoid divergent or conflicting priorities and intervention strategies.

A positive influence of the NDIS is having the participant, child, family or both, leading the planning process as this allows for the voices of the children and their families to have a major influence on the development of services. Aubrey and Dahl (2006) state that this is necessary for increasing autonomy for recipients, which is an explicitly stated goal of the NDIS (McDonald & O'Callaghan, 2015). It is envisaged that should the improvements in service delivery identified be implemented, the NDIS has the potential to lead to better long-term outcomes for the

family and the children themselves in Australia. Publication of research in this important area can add knowledge that assists Australia, and other nations grappling with similar issues, in providing better services for Indigenous people with disabilities.

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