Submission: Towards a regional rural disability strategy

This submission to the Productivity Commission is submitted by a group of Bendigo regional rural service providers. The working group has comprised:

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1. Overview

We strongly support the directions for the NDIS as a social insurance scheme for people with severe and profound impairments arising from developmental, acquired (through accident or illness) and psychiatric disabilities, and their family carers.

We endorse several roles for the NDIS directly funding individuals and their families; and to enhance service system effectiveness. These two roles are intertwined and our submission seeks to outline what this dual set of activities could mean in a regional rural location.

The aim for our submission is to comment about issues facing people with disabilities, families and service providers in regional rural locations. That is, areas where there is a larger regional centre which serves surrounding small towns and localities. Regional rural localities are typified by Bendigo, a large inland city, and the surrounding smaller towns and population centres, up to drive 2+ hours away, where Bendigo is the service city for many of the more dispersed population centres.

Experience has shown that metropolitan models of service delivery cannot be assumed to work in regional rural areas and that it doesn't have to be assumed that populations of this magnitude must rely on metropolitan specialists.

The issues and the possible solutions are not the same as either metropolitan or remote localities. The typical response to resourcing rural communities has been with hub (metro) and spoke (rural) areas. These approaches rely on metropolitan based staff (often travelling long distances from their usual work locations) who don't know regional rural communities;

and don't create links between rural providers and individuals in 'like' communities. The result has been limited attention to locating specialist knowledge in regional areas; networks which are metro-centric whereby regional rural providers know more about metro service delivery than other similar areas; or notions of multi skilling of staff occurring in the absence of tailored information and training relevant for regional rural localities (for example, the challenges of a sparse workforce and staff recruitment and supervision). Traditional 'hub and spoke' approaches in Victoria also haven't recognised or anticipated the possibilities to develop specialist resourcing roles in the regional cities which recognise and build regional rural collaboration within a network where all of the providers operate.

We believe the characteristics of regional rural locations means we are well placed to take real advantage from possibilities offered through the NDIS to make a reality a good life for people with disabilities and their families in their local communities. The scale of regional cities, like Bendigo, lends themselves to innovation and creative links across sectors because of being big enough to have local cross sector initiatives and not so big as to have created impenetrable silos across the critical areas of education, employment, justice, health and so on. There is the potential to foster and support leadership – from people with disabilities and their caring families, from the provider sector, from local government, from regional universities and other agencies.

We also are aware that our communities are changing: younger people are leaving, new people are moving here for a 'tree change' and traditional employment is no longer available through primary production. The population predictions for Bendigo in the next decades are that it will increase by 50%, furthering our vision of Bendigo as service centre supporting specialisation and service development for the people living in this regional city and surrounding smaller towns and communities. Disability support has the potential to create new and locally based careers for people with disabilities, and for those providing disability supports.

1.1 Structure of the submission

The submission aims to outline issues from the perspective of regional/ rural Victoria. Some of our comments apply to the NDIS more generally. The submission is structured as follows:

- Context: regional rural, difficulties, opportunities
- What's wanted from an NDIS
- Towards a regional rural disability strategy:
    - Having a package doesn't create services: need

- Capacity building: within organisations, and workforce development
- Infrastructure development and cross sector initiatives
- Community strengthening in small towns and localities
- Service delivery models for regional rural
    - Attention to quality service delivery regardless of how many providers
    - Collaboration between providers
    - Resourcing, training etc
    - Research and trialling (eg cross sector for many people with various dual disabilities

2. Context

2.1 Principles underpinning our submission

Regional rural service providers are committed to people with disabilities and their families being able to live and be supported in the rural areas of their choice. We already recognise that this may mean different service models and approaches from the metropolitan areas. We believe the NDIS is an opportunity to establish the parameters of good practice in disability support for rural areas, in new and relevant ways. We welcome the emphasis on maximising people's independence (and therefore reducing need for paid supports wherever possible). This means a rejection of 'caring' as the predominant role for staff and an emphasis on staff having competence to promote skills development and independence of people with disabilities as well as enabling and facilitating community relationships and opportunities.

Our starting premise is people want to live in regional rural communities and should be supported to do so. People know that living in rural areas is not the same as living in more densely populated areas. It is not possible to have the same structuring of opportunities and services available to people in rural areas as in metropolitan. Service delivery costs will be higher in rural areas in some aspects; just as it will be higher for people with high support needs. However there are greater opportunities for meaningful community involvement and participation. People with disabilities can be well supported and live good lives. Regional rural communities need people with disabilities and their families to stay local and not move to bigger towns. There is potential to build on an ethos of 'we support our own' in many communities while recognising that people with disabilities are part of the rich mix of all Australian communities. There is good evidence that moving people away from their local

communities impairs the likelihood of acceptance, community support etc. (for example Mansell et al 2006.)

> *Where those with intellectual disabilities are the siblings or children of local people, acceptance into the community may be easier to justify or achieve. However, where people have been displaced from their local community, treated as a commodity and traded across community boundaries, the basis on which someone can be introduced into a community as part of that community has disappeared. The disruption of family and community ties was an important disadvantage of the institutional era of services but it lives on in some market-based systems* (European Intellectual Disability Research network, 2003).

Supporting people with disabilities in local areas can be thought of in terms of community, development and capacity building, job creation and increasing productivity for those local areas: for staff, for people with disabilities and for family members who wish to return to work. There is a belief within some rural communities that they are more able to informally support people, (therefore reducing formal support costs and/or achieving a better quality of life) and this potential has been under resourced and under researched. This does not mean using volunteers when paid staff are really needed, but identifying legitimate roles for families, community members and paid staff as part of an overall approach to supporting people with disabilities in their local area.

2.2 Individual funding does not create services

We welcome an individualised approach to service delivery and funding. However, it is not the whole answer to creating quality supports for all Australians with disabilities. Individualised funding and support does increase the likelihood of tailored planning and supports so people can live as they wish and not as providers determine. However, Victoria already has individualised funding arrangements for many people. Individualised funding and support alone does not assist individuals or their caring families to come together for mutual support, information, and self advocacy. In addition, the experience in Bendigo, a comparatively large regional city surrounded by much smaller towns and localities, is people with disabilities and families can have individual funds allocated but there are no suitable services to provide that support. There are no services available because:

- Individualised funding does not create services in localities without infrastructure or for low frequency circumstances
- In areas with small populations, there will be numerically few people with disabilities and few people for the potential work force.

- Within the current funding it is too costly to transport staff from larger population areas to smaller ones.
- It is very difficult to train, supervise and manage staff across too many diverse locations separated by distances of travelling time one hour plus.
- Current funding levels do not match agency costs of delivering local services with trained and supervised staff
- There will not be as a wide selection of services (as per metropolitan areas). Frequently there are very smaller services struggling with the requirements for contemporary accountability and adequate infrastructure.
- Fu nding does not recognise well trained staff. Even when individuals are funded, little attention has been paid to recompensing staff and agencies for staff trained consistent with research best practice. The reduction of the disability workforce to a largely untrained/ certificate trained workforce means agencies need to additionally train staff if best practice wanted in (such as positive behaviour support)
- The effect of two or three providers in some localities is to split the potential small workforce, making it impossible for staff to get all of the work from one agency, making staff less likely to be committed to staff training or meetings. Inconsistency with staffing and service delivery is a key threat to good outcomes for people with disabilities.
- Some rural services will not be viable due to the greater transport costs; including greater supervisory costs etc. Services will be more expensive in some areas and this is not reflected in funding. Conversely, service received will be less effective.

Service development for people with disabilities will not respond like a pure market model. Service delivery is not 'cost effective' for providers in the same way as may be the case in more densely populated locations. 'Competition' between organisations may simply fracture the small available workforce or may be meaningless as there is only one provider in a given area. Organisations who do not know a local area well can struggle for acceptance and effectiveness. If market forces dominate then rural/ isolated and people with exceptional needs and circumstances people will miss out on quality service delivery. It is frequently said rural staff need to be 'multi skilled' while this may be true up to a point, indicators of quality service delivery are needed regardless of the service models, or rural people with disabilities will not be supported in ways which maximise independence and participation.

2.3 Simplistic 'choices' can perpetuate poor services

Rural areas highlight the extent to which 'choice' has been reduced to a simplistic notion where 'individuals can choose which service they want' in the absence of understandings of service quality responding to people disability support needs and improving quality of life. People shouldn't be able to choose services which don't reach minimum expectations for achieving personal outcomes.

We argue regional rural people can get high quality services, but the path to this is not choice of services in areas where such multiplicity is not feasible or available.
We argue that the overriding choice people are making is to stay living in a rural area. If equity is one of the guiding principles for the NDIS, then indicators are needed about the ways to support people with disabilities meaningfully, based on research about good practice in these rural areas.

If people with disabilities have individual funds, and there are no providers, it has become acceptable to have untrained family, friends and neighbours undertaking roles in an unsupervised way – all in the name of 'choice'. However, such 'choices' do not entail a minimum standard of service delivery with good accredited staff as is insisted upon in other areas of publicly funded service delivery. Individuals and families may also be choosing more conservative service options because other arrangements are too uncertain. People in regional rural areas become vulnerable to poor standards of services and support when there is no requirement to implement best practice.

Best practice means achieving personal outcomes for individuals ie people with disabilities live a demonstrably better life as a consequence of the support received. This must include attention to people's social and cultural lives and not be restricted to physical and personal care. If there was clarity about goals and outcomes for the service system and for individuals then rural service systems can structure to achieve these.

4. Towards a regional rural disability strategy

The health sector in particular has argued successful for a rural strategy. There are parallels in the disability sector. We are arguing for approaches improving practice beyond direct support staff and relevant to regional rural locations.

4.1 What a regional rural strategy could tackle

A market based models assume competition between agencies is the best organising principle. Regional rural communities experience the best service responses when there is interagency cooperation, albeit recognising that agencies may 'compete' in terms of project funding or relevance for specific individuals. With a backdrop of inter agency cooperation for planning the service system, there is potential to:

- Within the national disability strategy to recognise differences in service models and responses between metropolitan, regional and remote localities
- Have a locality-based approach to accreditation and best practice whereby how best quality is achieved varies but not the expected level of quality
- Develop coalitions of providers by locality, by expertise; and to create alliances to source common projects.
- Promote infrastructure and draw attention to possibilities for some of these costs to be funded in different ways e.g some of the Health IT roll out was funded separately from the service system.
- Have a combined approach to the big barriers of transport loading; It and infrastructure development.
- Possibilities for community centres in small localities eg with mobile library.
- Links to universities for research, staff training
- Establish regional people with disabilities/ family-carer/ provider alliance
- Tackle cross sector, silo issues which are entrenched in larger communities. Eg mental health has a part time court worker – could broaden.

4.2 A different approach to work force and service development

It is important to have specialist knowledge available about the best ways to support people with different disabilities. Such specialist knowledge requires sector development workforce which carefully integrates the roles of professionally trained staff and certificate trained staff. This has not occurred in Victoria as there has been a resistance in government to specialised service delivery for people with different disabilities. The critical issues for regional rural localities then become being able to structure organisations and service responses which can access specialist information and training. It's not possible or

necessary to have highly specialised agencies in each locality but that specialist information and resourcing does need to be available. Regional rural communities do need more multi-purpose services - but not isolated, and under trained services.

Different solutions will be possible in different areas depending on existing infrastructure, history and relationships between and within communities. The expectation that all programs are 'rolled out' uniformly across the state/ nation does not serve regional and rural communities well. The NDIS is an opportunity to introduce more clarity about what si expected to be achieved and encourage different ways this can be done which are most relevant for specific populations ie it must exist, and then to consider rural organisational development, workforce and rural community strengthening needs.

We know management and service delivery is better if supervisors are closer to staff. The challenge in regional rural areas is how to achieve supervision with dispersed and individualised service delivery.

4.3 Regional rural understandings of roles and relationships

Particularly in regional rural areas we want to explore better understandings of:

- The skill set staff need for best practice
- Legitimate roles for families arising from the strengths of family relationships. There is concern about the employment of family members as an option when there are staff shortages. We argue that if families are doing the equivalent of a paid staff role, they too need training, supervision etc.
- We want to support people to have a voice and to have good information about quality services. There do need to be sensitivities in small communities about privacy and making complaints. For example, how to respond to the person with a disability separately from their family.
- Delegated decision making for individuals with disabilities who can't readily make daily and major life decisions.
- Boundaries between family caring roles and paid roles (noting that some families do undertake these roles if they choose) what could be if families chose),
- Boundaries with what volunteers may do in formally organised ways, such as leisure buddies, or community development approaches connecting community members.

4.4 Options to staff solutions

Staff may not always be the best option or the available option. We want to explore workforce development and support delivery using:

- Video technology for communication, training/ supervision/assessment, secondary consultation, cyber offices
- Better use of aids, equipment, technology, dog assist etc
- Clearing house for information relevant to rural staff, individual and families ie options to specialisation where expert staff travel at high cost.

4.5 Ways to coordinate and concentrate resources

We want better ways to concentrate and coordinate resources such as,

- Support worker on-call for immediate advice across a nearby locality, or across agencies. These types of initiatives are difficult to arrange and sustain if relying solely on individualised funding.
- Better links to heath, local government and education systems/ resources and ideas about how to use the resources which are very local.
- How to use expertise from other sectors, such as mental health, aged care assessments.
- Developing a critical mass of staff in small towns which is coordinated, doesn't split workforce across agencies and minimises fractional employment for people who want more work. This is not the same as 'agency staff' whereby despite being a flexible staff pool such staff are not to aligned to specific values of each employing organisation, and may not be trained or participate as if in the organisation.
- Choice of providers is silly in rural areas if there are small numbers of people wanting services, small potential staff pool (and supervision from another locality). Other possibilities include preferred provider or consortium of providers with expectations for performance. Put effort into accreditation, service quality – rather than superficial processes or simplistic responses to choice. Put teeth into accreditation and how people's complaints are responded to. If single provider (or coordinated system to maximise use of resources) still want various service responses possible
- Hubs for staff eg for safety, GPS monitoring,

4.6 Comparisons with the health sector

The developments in the primary health sector arising from a rural health strategy suggest approaches applicable in our context. NDIS has the potential to support long term regional rural process that builds expertise and capacity to improve the lives of people with

disabilities through improving performance of disability providers in a given locality. If parallels are drawn with the Divisions of General Practice there is potential to create a well resourced geographically based professional body which undertakes activities such as community development, accreditation (staff and organisations); advice re business operations; assists with recruitment; is a base for specialist supports and projects; seeks funding; undertakes research; builds collegiality; brings together isolated providers and practitioners and is locally managed. Such a body could also undertake aspects of 'back of house' functions for smaller organisations such as: insurance, payroll, technology by providing advice and/or delivery pooled. Such a body needs to be well resourced: ie powerful; employ leadership staff and not only administrative staff; and be evaluated. Such a body creates a 'me too' effect rather than insisting groups participate. This approach has proved effective for GPs across the nation.

5. What's wanted from an NDIS

This submission supports a model of 'no fault' social insurance, similar to TAC with:

- A national disability strategy relevant to all people with disabilities which includes a regional/rural disability strategy.
- An emphasis on impairment, not diagnosis alone, means that people with less severe disability (particularly people with mild to moderate intellectual or psychiatric disability) are eligible for direct funding and get effective services that enable them to gain independence and negotiate critical times in their life. It is possible for this group to be left in a holding pattern with support that maintains only basic functioning. Without effective support, which at times may need to be intensive support for finite periods, this group of people will not develop independence (thereby reducing their need for formal supports in the long term), or have the chance to gain employment. People with various mild to moderate cognitive impairments are over-represented in criminal justice system, unemployment and mental health systems. This could be reduced significantly with targeted and effective support services.
- A central NDIS role including policy, monitoring, review, system strengthening, wider education, research and population-based planning. This would include legislation, accreditation and monitoring of all providers – be they not for profit, for profit and individual practitioners. Current Victorian legislation only not for profits fall within regulatory framework.
- A state/ regional role in claims management, monitoring, review; cross sector strengthening to improve the lives of all people with disabilities through

partnerships, initiatives and leverage with other key sectors, such as employment, education, health etc.

- Transition to NDIS based on priority to early intervention, especially children. There is concern for people currently in system with inadequate funds who will need re-assessment for lifelong needs.
- Individual funding with:
    - Eligibility for individualised funding for people with severe and profound impairments arising from development, acquired and psychiatric disabilities based on predictable and fair processes, decision and review mechanisms.
    - Individualised and self directed funding with assistance and delegated decision making (or proxy) arrangements where people need assistance with decision making, often arising from intellectual disability, ABI or psychiatric disabilities.
    - Lifelong liabilities and incentive to reduce costs through adoption of best practices in disability support which maximise independence
    - Possibilities for co-contributions with private resources and community resources
    - In relation to people in regional and rural communities, an allowance in individual packages for people living in non metropolitan areas to fund transport and supervision and training for dispersed support staff.

- Administrative processes including:
    - Functional assessments – not diagnostic alone.
    - Separation of the funder and assessor roles
    - Separation of the funder and provider roles

- Want research based in rural and regional communities about support effectiveness; minimising impact of disability; and specialist knowledge about optimising quality of life for people with various disabilities.
- Pursuit of approaches to partnering and collaboration using models from others sectors, such as Australian Arts Business Foundation (ABAF), Research & Development programs between industry and universities.

Significant reform of the disability support systems requires a long term strategy for change. Everyone will need to feel responsible for the NDIS scheme working (ie achieving quality outcomes) for people with disabilities and their families; and being financially viable.

The current system has neither ensured quality outcomes for people with disabilities nor encouraged best use of funds through attention to effective practice and standards. It will be a dramatic change to replace gate keeping and rationing of funds with effective practices which aim to maximise people's independence and quality of life. This requires significant re-training for staff, including those undertaking the claims management roles, to attend to good practice, services' standards and personal outcomes relevant to people living in regional/rural locations.

6. Concluding comments

We are aware that the NDIS cannot 'solve' all of the difficulties begin experienced within disability support and for people with disabilities. These comments hopefully assist with the Commission's deliberations about what are the first order issues to be incorporated in the new system, particularly given the bulk of submissions necessarily emanate from metropolitan perspectives. We anticipate continuing to work on these issues and would be pleased to respond to any specific questions from the Commission.

References

European Intellectual Disability Research Network (2003) Intellectual disability in Europe: Working papers. Canterbury: Tizard centre, University of Kent at Canterbury

Mansell, J., Beadle-Brown, J., Skidmore, C., Whelton, B. and Hutchinson, A. (2006) People with learning disabilities in 'out-of-area' residential placements: *Journal of Intellectual Disability Research, 50* (II), 837-844.