



Reform of the disability service system in Australia – Will greater resources increase the social inclusion of people with intellectual disability.

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Australia Disability Policy - Good Intentions

National Disability Strategy 2010- 2020

‘committed to a unified, national approach to improving the lives of people with disability, their families and carers, and to providing leadership for a community-wide shift in attitudes

- Inclusive and accessible communities
- Rights protection
- Economic security
- Personal and community support
- Learning and skills
- Health and wellbeing

**Signatory to the United Nations Convention on Disability 2006
Rights**

Legislative and Policy Response to Disability – to date

Welfare

- Compensate for disadvantage - lack of potential or additional costs. e.g. Federal – Social Security Legislation - Disability Support Pension, Carers Pension, Mobility Allowance, Child Disability Allowance

Service Based

- Infrastructure of services to support individuals & foster potential
- How funded, organised, delivered, on what basis, to whom
 - Community based specialist support
 - State level - accommodation, education, community access and personal support
 - Federal - supported employment
 - Underpinned by strong values but not as of right - no entitlement
 - 1986 Cmw Disability Services Act, 2006 Vic Disability Act

Enablement

- Programmatic not individual - support inclusion and participation –
 - Affirmative action employment, Disability Action Plans, Community Development, Companion Card

Rights

- Protect from discrimination and less favourable treatment exercise rights, access to mainstream
- Federal Disability Discrimination Act - State Equal Opportunity Act

The Need for Reform

Ineffective and unsustainable disability service system

‘The current disability support system is underfunded, unfair, fragmented, and inefficient, and gives people with a disability little choice and no certainty of access to appropriate supports. The stresses on the system are growing, with rising costs for all governments’ (PC, 2011)

Crisis driven and unmet demand

‘disability services are often in crisis mode, with fragmented programs, inadequate provision of services and high levels of unmet demand’.

Require 2 x current expenditure of \$6.2 billion.

Inequitable - level of support people receive is heavily influenced by where a person lives and how they acquired their disability.

Fragmented structure of the disability system, and a lack of coordination between the pieces, have made it extremely difficult for service users and their families to access services.

<http://www.pc.gov.au/projects/inquiry/disability-support/report>

Poor Quality Services – Not delivering desired outcomes

Examples for Research

Findings from Kew studies – moving from Kew to the community

- Present but not participating
- Small social networks family and co-residents ‘distinct social space’
- Staff don’t accept participation is possible for people with more severe disabilities

Findings from ‘Encounter’ study

Social inclusion is not just about lasting relationships with family and close friends, but also about our more fleeting interactions and connections with acquaintances and strangers (actions of workers support or detract from encounters or being known or belonging – clips x 3)

Illusions of inclusion - poor support

- Going out into the community but little interaction (46% time at bowling disengaged).

Frank looked lost, and appeared unsure of what to do. After 5 minutes, he asked a support worker from another service for help in finding his team mates. Starting at the screen (score board) was his default position.’

Impact on Quality of life

Findings from Volunteering study (Bigby et al., 2014)

- Default position of services and gate keepers is special and separate groups
- Community groups are willing but anxious about inclusion
- Some groups see the place of people with disability in services not 'their' place

Findings from studies of group homes (Mansell, Beadle-Brown Bigby, 2013; Bigby et al., 2012)

- Variability outcomes (slides over)
- High levels of disengagement
- Consistently poorer outcomes for people with higher support needs

Employment rates very low

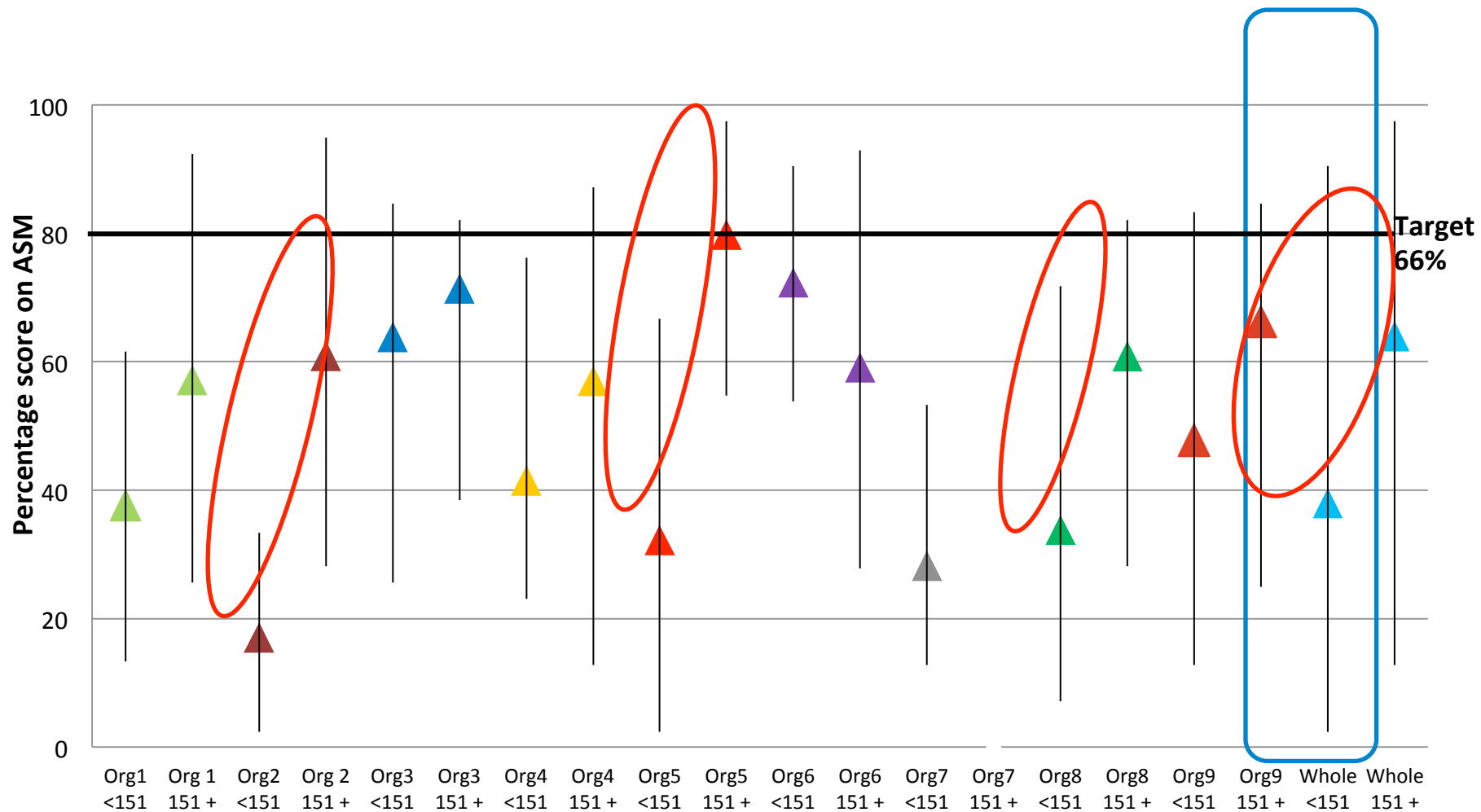
- OECD 21/29
- Disability labour force participation rates of 52.8% compared to 82.5%
- Unemployment rate of 9.4% compared to 4.9%
- Participation rates even lower for people with intellectual disability (40.9%), people with acquired brain injury (35.6%)

Outcomes and Staff Practice High and Lower Performing Organisations


Sample average and people with higher support needs – variability across and between groups

	Whole Sample	Org 1	Org 2	UK study Good active support (Ashman, Beadle-brown, 2006)
Engagement in meaningful activity and relationships	47% (31%)	64% (54%)	25% (16%)	60% (54%)
Quality of Support (Person Centred Active Support)	49% (38%)	67% (64%)	28% (12%)	79% (79%)
Time spent receiving assistance and contact from staff	12 mins (11)	18 mins (15.5)	7.5 mins (6)	23 mins (25)

Active Support: People with More Severe Disabilities do much worse than People with Less Severe Disabilities



- More able people experience better active support - exception Org 6 (& Org 7)
- Only 3 orgs provide consistent good active support for more able people

 Sig difference

National Disability Insurance Scheme (NDIS)

Aims and indicators of success

‘once in a generation economic and social reform agreed by all governments and will benefit all Australians

Insurance scheme – not welfare – long term financial viability – saving \$ and adding to GDP - Won on the economic arguments

The long-term **economic benefits of the NDIS are estimated to exceed its costs**, adding around 1 per cent to gross domestic product and saving \$20 billion per year by 2035.

Must demonstrate its viability and outcomes

Vision

Optimising social and economic independence and full participation for people with disability.

Mission

Building and managing a world leading National Disability Insurance Scheme for all Australians.

External independent evaluation of outcomes Flinders University against key indicators

The NDIS Basics

- A national scheme to provide insurance cover in the event of significant disability.

3 Tiers

- Individualised funding of support packages all people with significant and permanent disability approx 460,000 people
- ‘Reasonable and necessary supports’ across the full range of long-term disability supports currently provided by specialist providers.
- Cost approximately \$13.5 billion - \$6.5 billion above current
- Tier 2 Providing information and referrals people with disability
- Tier 3 Mainstream community services accessible – to everyone
- Services such as health, public housing, public transport and mainstream education and employment services, would remain outside the NDIS
- Launch sites in 2014 - progressively expand to all significant disabilities by 2018-19
- Parallel scheme to cover all catastrophic injury by the end of 2015

Goals and Success Indicators

Goal 1 People with disability are in control and have choices, based on the UN Convention on the Rights of Persons with Disabilities.

Success Indicators:

- People with disability plan and exercise choice
 - [Choice and control - respect for dignity of risk]
- People with disability achieve their goals for independence, social and economic participation
 - [employment – learning – participation]
- Care arrangements are sustainable and forward looking
 - [adequate support and certainty over life time]
- A healthy, innovative and efficient market for disability services which supports a culture of choice and control
 - [Support care by families and other informal sources]
 - [Build community capacity for people who do not receive funding]
 - [More than individual packages – community capacity more widely]
 - [Significant change to funding for services – no block funding reliant on individual purchase]

Goals and Success Indicators

Goal 2 The National Disability Insurance Scheme is financially sustainable and governed using insurance principles

Success Indicators:

- The NDIS is collecting and reporting appropriate data for actuarial analysis
- Quarterly monitoring reports and annual financial condition reports are on track and appropriate
 - [accurate, timely, long term data]
 - [decisions based on actuarial advice and best evidence] [early intervention and effective interfaces with mainstream]
- Benefits are realised from targeted investment strategies in enhanced disability support
 - [influence and investment for capacity – workforce – research - housing \$550m pa]
- Short-term and long-term costs are effectively estimated and managed
- The NDIS research and evaluation strategy is integrated into the insurance and actuarial reporting process -[effective interventions what works what doesn't]
- A healthy market is developing that increases the mix of support options and innovative approaches

Goals and Indicators

Goal 3 The community has ownership, confidence and pride in the National Disability Insurance Scheme and the National Disability Insurance Agency.

Success Indicators:

- Access, reasonable and necessary supports and administration costs meet community expectations
 - [accepted understanding of reasonable and necessary by community - consultative, retains community support, builds confidence – stakeholder engagement] [threat is older people left out]
- People with disability are welcomed in community and easily able to access support from mainstream services
 - [work by all govts on re reasonable adjustments physical and social infrastructure – powerful influence on policy – community awareness, information re disability, model inclusive practices in employment 11% end of 2014]
- The NDIS reports publicly on its performance (quarterly reports]

Creating an insurance scheme: four insurance principles:

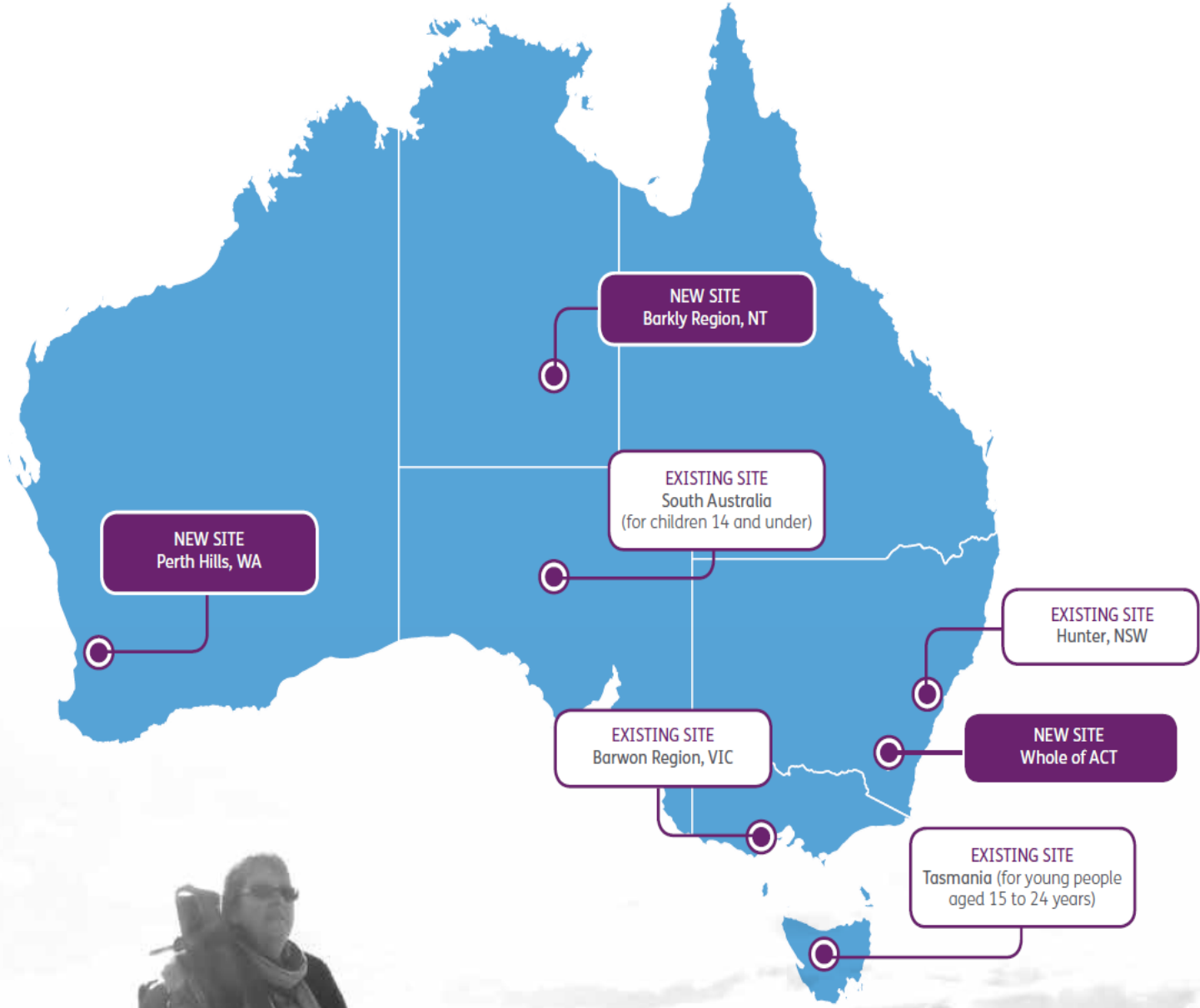
Actuarial estimate of long-term costs: utilisation and costs ensure the Scheme is financially sustainable.

Long-term view of funding requirements: unlike historic welfare schemes, the NDIA takes a lifetime view of support and Scheme sustainability, seeks to maximise early investment and to support the contribution made by families, carers and the community.

Investment in research, innovation and outcome analysis: to support insurance-based governance and long-term planning, the NDIA will invest in research and will encourage and build the capacity and capability for innovation and outcome analysis.

Investment in community participation and building social capital: to further support long-term investment, the NDIA will, over time, invest at a systemic level in addition to providing for individual supports. This includes

- (a) encouraging the use of mainstream services to increase social and economic participation of people with disability,
- (b) building community capacity and social capital, which will be particularly important for people with disability who are not participants. The ongoing implementation of the National Disability Strategy by governments will support this work.



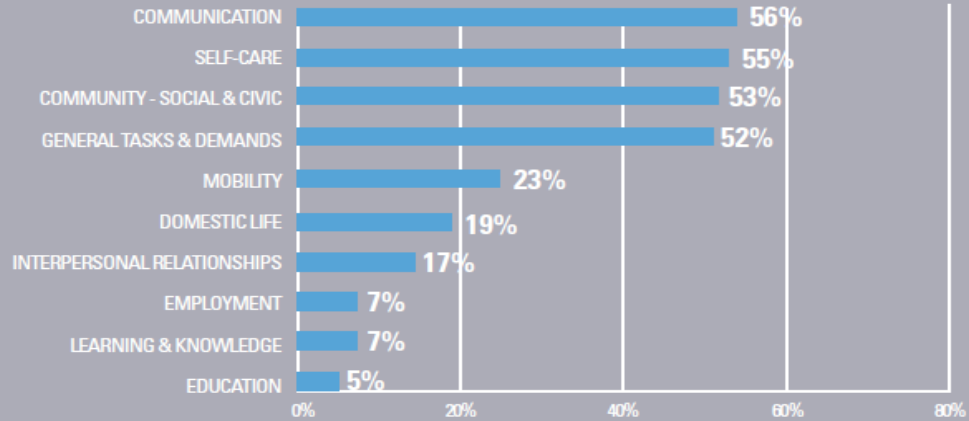
Pilots and roll out – scale of change

- 4 Pilots July 2013 different groups Tas, NSW, Vic, SA gradual transition
- First year 8,585 people eligible, 7,316 receiving – Vic largest, 2907 - fairly even age groups 1% 65+
- People with intellectual disability – biggest single group (30%) probably more if include developmental delay
- Majority packages managed by NDIA 2% self managed
- Average cost \$38,200 - variable across groups and ages
- \$130.9 million to participants—within the funding envelope of \$148.8 million.
- July 2014 new pilots WA x 2 (signs of different approaches), NT, ACT
- Trail sites until 2016 incremental roll out from 2016- 2019
- Cost Estimate \$16 b (\$11b in 2017-18) more than double current
- Funded through States, Cwth, and 0.5% medicare levy
- Complex and compound funding model (see analysis Richard Madden NDS conf)
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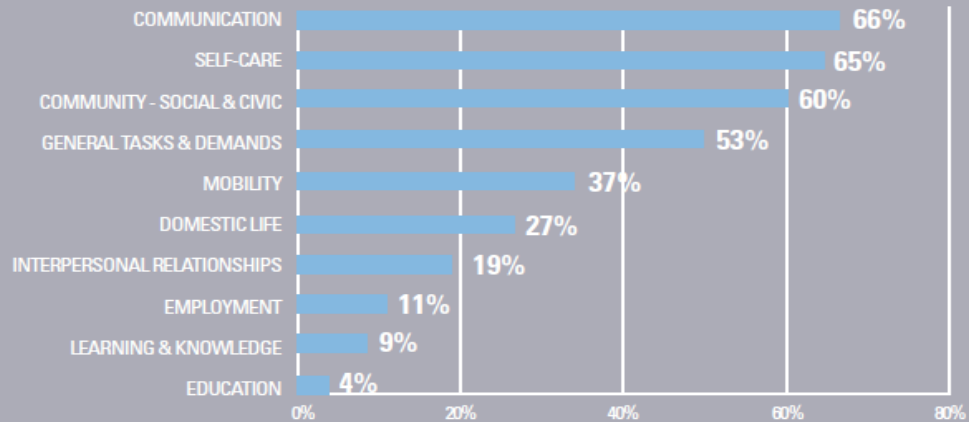
Primary Disability	NSW	SA	TAS	VIC	Total
Total	2268	1355	786	2907	7316
Intellectual Disability	32%	11%	47%	33%	30%
Autism and Related Disorders	21%	33%	30%	24%	26%
Other Neurological	14%	3%	6%	10%	10%
Developmental Delay	3%	16%	2%	6%	7%
Cerebral Palsy	6%	7%	8%	5%	6%
Global Developmental Delay	2%	14%	2%	2%	4%
Other Sensory/Speech	3%	8%	1%	3%	4%
Other Physical	5%	3%	2%	3%	4%
Schizophrenia	4%	0%	1%	4%	3%
Other Psychiatric	3%	0%	1%	4%	3%
Deafness/Hearing Loss	3%	5%	1%	1%	2%
Multiple Sclerosis	2%	0%	0%	4%	2%

FIGURE 2B: TRIAL SITE PARTICIPATION BY FUNDED SUPPORT CATEGORY AND STATE

TAS



VIC



Political context – consensus?

- Every Australian Counts Campaign – united front by disability sector based on consensus
- Implemented a year earlier than recommended - Locked in by labour
- Bi partisan support - not affected by budget
- Future Fragility - Commission of Audit – delay – change structure reduce independence – high level of scrutiny joint parliamentary standing committee
- Continue undermining in the media – Australian – cost blow outs, too soon, b'cracy, blame Gillard
- Forever raised the profile of people with disability -
- Implications of united front little debate about the detail or challenge to some of the assumptions about consumers and markets – choice and control – complexity of these issues for people with cognitive impairment
- Fine line of raising issues without undermining
- But whose voices are being heard ? Service providers – impairment specific peaks and lobby groups - almost no voice of people with intellectual disability
Bias towards simplicity – take a look at who is speaking in joint part committee

Design assumptions

- Market model – demand driven deliver more effective and efficient
- Individualised funding enable greater person centred, flexibility, consumer choice and control
- Perfect market – capacity to deliver quality and quantity and adjust to demand
- Perfect consumers – know what want – judge quality – use influence to change or if not happy
- Capacity to make a claim, explicate needs and wants, locate and chose providers.
- Every one can self advocate or has family a family who can do so
- ‘Reasonable and necessary’ disability supports - separate disability related support from other types of support that everyone needs
- Predicated on access to mainstream – responsiveness of the mainstream
- Dominant Attendant care model - currency is hours of support – relatively unskilled – can be directed – values rather than qualifications

What has been learned from the trails

- Enormous amount of activity and engagement – services, advocates, media
- Investment in consultation – reflected in changes – unlikely to be the same in another 2 years
- Mainly focus on internal process of planning and purchasing – too soon for outcomes
- Concerns re processes – Most satisfied with outcomes
- Many of issues relevant to people with intellectual disability
- Planning processes - more complex & taking longer than thought – too fast – inconsistent - greater recognition of knowledge held by providers – realisation of knowledge and skills involved – need for support and advocacy increasingly recognised
- Ideas about pre planning, interim plans?
- Plan coordination and implementation more complex than thought – issues re funding services for coordination – who does it now say building case management and plan management capacity

What has been learned from the trails

Local Area Coordination - work of connecting and supporting inclusion community inclusion – not simply taking people along – longer and more complex than thought - examples are suggesting greater understanding [likely to be especially so for people with intellectual disability requires more change on the part of others – attitudes, inclusions, relationships, adjustments]

Dangers of simple roll over to existing programs – day programs and group homes

In Victoria haven't got to the one large institution Colanda yet

Providers not pleased - fixed prices costs – too low – differential between in states

Support clusters - things that don't fit easily into items with prices

Problems with cash flow and timely payments

New way of doing business – no longer block funded – major problem for those only in trail sites

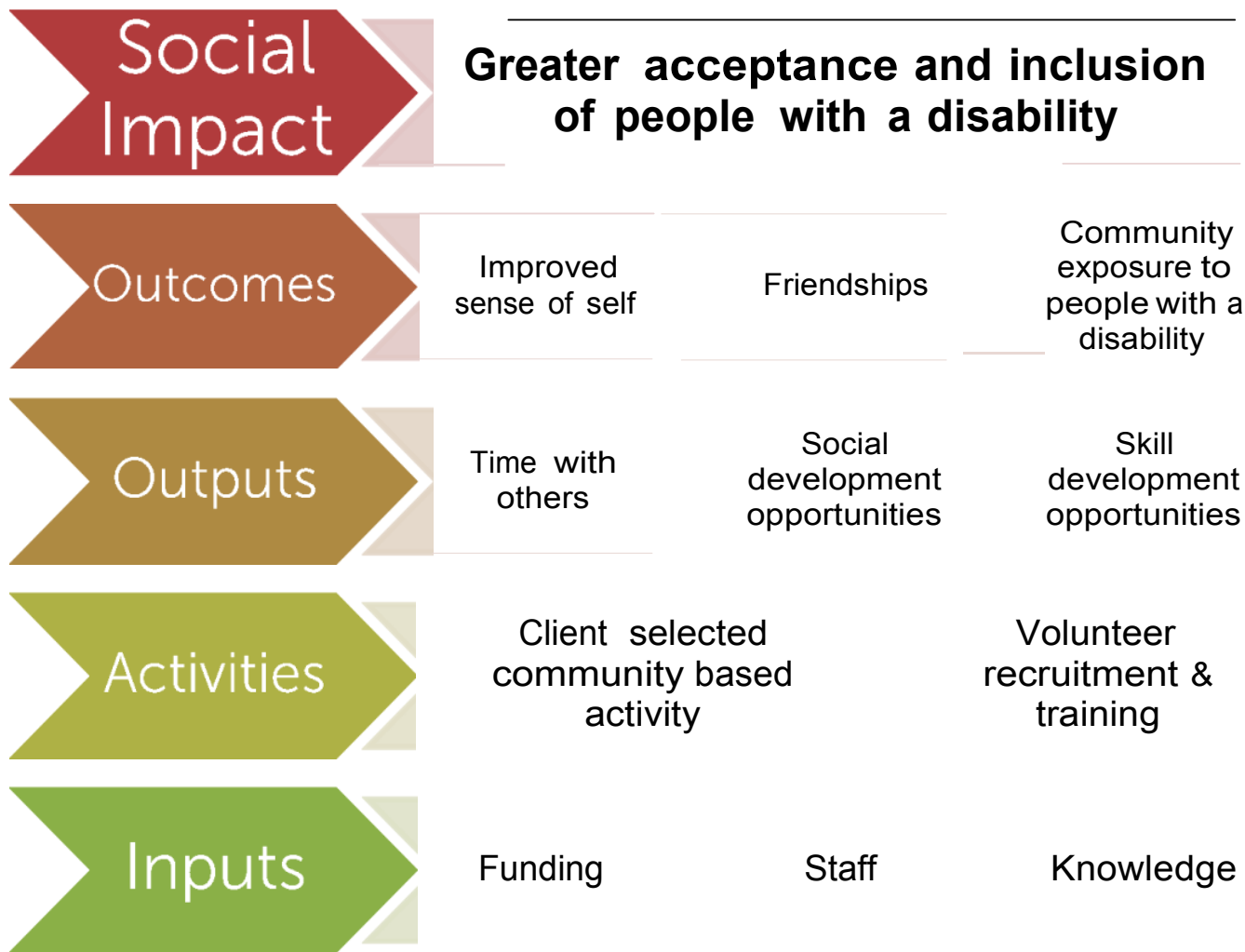
Impact on statewide – developmental services

Buying hours not outcomes - problems of no show – small snippets of time

New ways of thinking about support and services - redesign and rebranding

- Entry of the consultants – accountants, business development
- Not so much mission and values - survival – marketing
- New words –Products - Value propositions – Theory of change
- Benefits – greater clarity re what's on offer –
- May be easier to identify what you want - whether it is received
- Eg Inclusion Melbourne - theory of change

Our theory of change



- Improvement in physical & mental health
- Improvement in skills and abilities
- Decreased social isolation
- Increased presence of people with a disability

What the future might hold - under the NDIS

- More funds in disability support system – greater demand – housing and support
- More normative life course - less unmet need – more young people leaving home
- Increased separation of housing and support - different sources of funding
- Unbalanced supply – support and housing [NDIS will not fund housing]
- Greater diversity of housing tenure – rental, shared equity, private ownership – shortage of affordable housing [who funds housing?] [partnerships ?]
- Greater diversity of supported accommodation ‘models’
- Focus on design and use of technology to reduce support costs
- Break down of divide between day services and accommodation
- Greater competition - new providers and greater capacity for choice
- Impact of unmet need on quality will reduce – incompatible residents, lack of choice
- More pressure for high quality support – identifiable outcomes re independence, social and economic participation

Questions to Reflect on

- Will more money in the system change the quality of services and improve outcomes** - not necessarily [no unmet demand, less factors to undermine quality] [But other fully funded systems have relatively poor outcomes re inclusion and participation, Sweden – ? UK system multiple scandals disability and mainstream]
- Will the market provide what people need or want** [UK private providers shaping demand large specialist services convincing but not delivering]- [Vic almost a decade since individualised funding for post school options yet little change in offerings] [Need for demonstrations?]
- Will some people benefit most**– will outcomes be skewed [consistent from US and UK people with most social capital benefit most from individual schemes – better at making claims, self managing only small minority]
- To what extent are the voices and perspectives of people with intellectual disability embedded in the fabric of the new scheme?** [largely left out]
- How are people with intellectual disability being supported to make decisions** both about their plans and the services they purchase- are effective mechanism in place to mediate any differing views about their wants and who should support them to make decisions?
- What is the place of advocacy and self advocacy** as the new scheme rolls out?
- What energy is being directed to building mainstream capacity** of housing, health, education and criminal justice services?

Why is it important to focus on issues for people with intellectual disability

- Making claims, exercising choice and control, more difficult
- More vulnerable to abuse or poor quality services – harder to put rights into practice
- Significant marginalised group with poor social networks – less social capital
- Inherent bias against – thinking about change in the mainstream is more challenging – easier to think about lifts and ramps and braille
- Require different types of support other than personal care or equipment less linear [rely on skilled support to be negotiate social world, be engaged, participate , maintain relationships, trouble shoot]
- Reasonable adjustments to be consulted take longer – require more support and planning
- Not well represented by disability advocates - we use all the social model now – impairments not important
- Rely on others to support involvement and commentary – people with direct lived experience not involved and may not be sufficient

Whose choice

Making claims on a system

Complicated for people with mild intellectual disability and socially disadvantaged

(see O'Connor in RAPIDD

- proactive outreach to overcome exclusion;
- longer-term relationship building to achieve connection and understanding;
- deep listening to understand core messages;
- open-ended support to feel safe and achieve - hard to predict needs for those with chaotic lives
- creative support to open up opportunity.

Support with decision making - who ? how? mediating disputes

And for people with more severe disabilities with no family or dominant family ?

Australian Law Reform Commission suggesting new model supported decision making with principles, training, monitoring for nominees

Still know little re actual processes and practice - depends on relationships

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What should moderate choice

- When evidence about outcomes is contrary to aims of the schemes
 - Institutions – Clustered support - congregated segregated care few outcomes
 - Day programs – congregated – segregated
 - Sheltered employment – congregated – segregated, exploitative
- Should these be on the menu
- Do we have sufficient evidence about alternatives
- Few voices raised to date – some providers have major conflicts

Practice Matters - its not just hours of support Recognising the skills of working with people with intellectual disability

Data from the UK bad support costs as much as good

Skilled support to engage, current variability in group homes

Skilled support to work with people with mild to borderline ID or people with severe or profound ID don't figure in way support work is being understood

Workforce strategy project – down playing skills and qualifications focussed on numbers of workers - hours of support

Dangers of companionship model developed in Vic with individual funding – easier and simpler but in the long run poorer outcomes and increasing cost - use formal to develop informal – this is a service – with off shoots of CD

Lack strong evidence base but there is some there to use

Need for new language - multi factorial inputs to get out come

- Supported accommodation – direct hours, team work, practice leadership
- Inclusion in community groups -episodic hours, indirect work with groups, communities and direct hours

Checking what you bought - safeguarding

- How will people with intellectual disability be protected from abuse and poor quality services – regulation – registration- inspection ??
- Satisfaction is not enough
- More than audits of process

Collective Goods

How will collective things be funded - peer support, self advocacy, communication access

Need to be offered – promoted for free rather than sold because people don't know they need it

Thin markets – rural and remote areas, no one will provide too risky

Challenges

Generate a voice about people with intellectual disability

Leadership and advocacy – multiple sources, services, self advocates, academics, and advocacy within advocacy

Attention to support with choice and decision making

Attention to outcomes sought – types of service models and practices that will achieve these ‘

Tie outcomes to skilled support – get better are spelling out what this looks like

Limits to choice – not segregated, not congregated, not exploited

Engage mainstream in change, employers, health system

Some useful references to the Australian System

[National Disability Insurance Scheme website](#)

<http://www.ndis.gov.au>

Research and Practice in Intellectual and Developmental Disability – published by Taylor and Francis – has recent papers commenting on the NDIS

<http://www.tandfonline.com/loi/rpid20#.VGOP5FYxFFJ>

Living with Disability Research group at LaTrobe University, see web page and papers in library repository open access

<http://www.latrobe.edu.au/health/about/staff/profile?uname=CBigby>

<http://arrow.latrobe.edu.au:8080/vital/access/manager/Index>