



The Royal Australasian
College of Physicians

National Disability Insurance Scheme Session

Chairs:

- *Dr Jacqueline Small*
- *Dr Steve de Graaff*

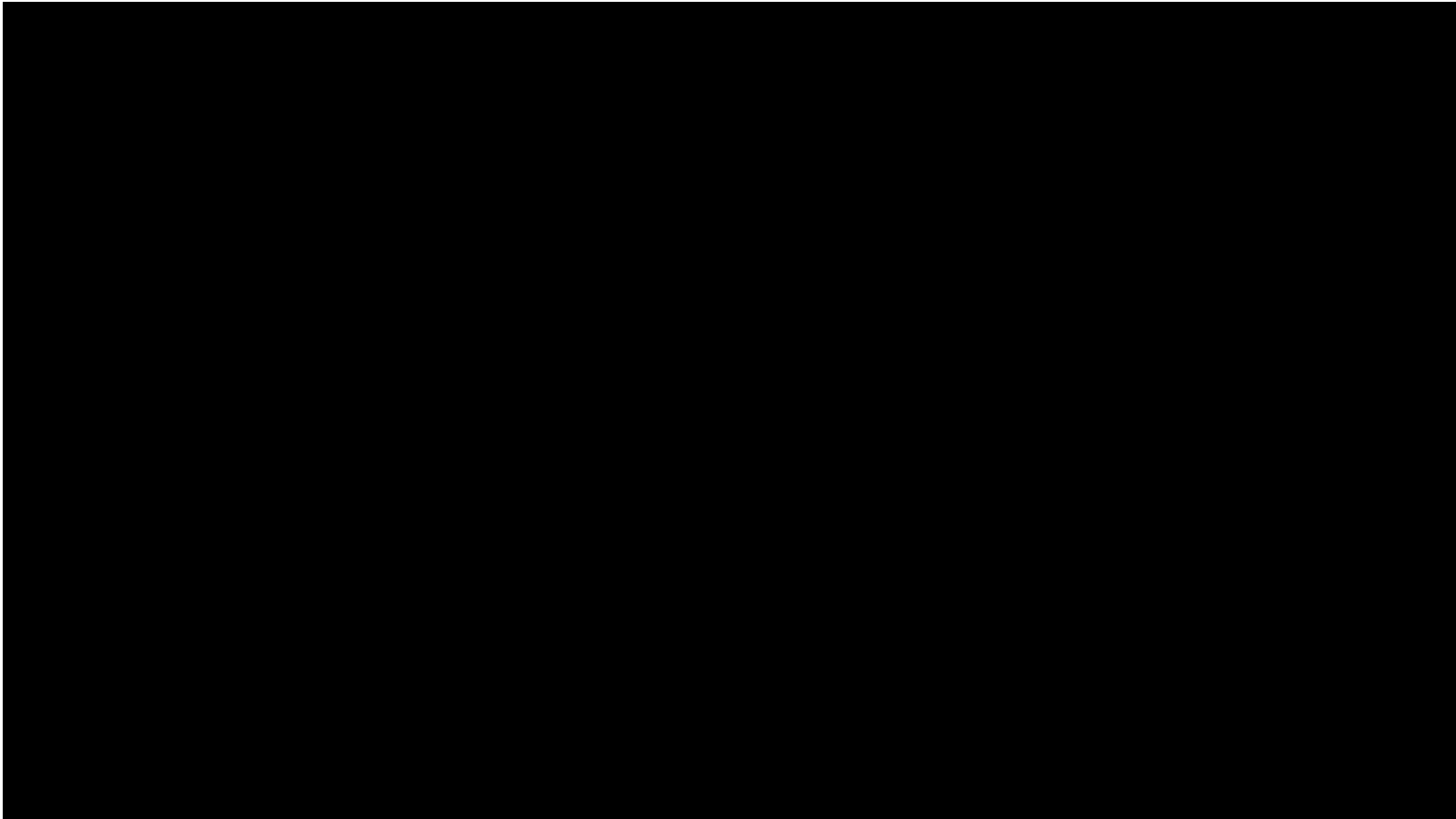
Speakers:

- Mary Hawkins
- Associate Professor Robyn Wallace
- Dr Nigel Stewart
- Dr Michael Bennett

The NDIS and ordinary life



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NDIS Rollout to Full Scheme

MARY HAWKINS

NDIA

May 2016



What is the NDIS?

- The National Disability Insurance Scheme is often referred to as the NDIS.
- It's a new way of providing care and support to people with disability.
- The NDIS supports people with disability to participate in and contribute to their community.
- It provides certainty that people with disability will receive the care and support they need over their lifetime.

NDIS principles



- People with disability have the same right as other members of the community to realise their potential
- People with disability, their families and carers should have certainty they will receive the care and support they need
- People with disability should be supported to exercise choice in the pursuit of their goals and the planning and delivery of their supports
- The role of families and carers in the lives of people with disability is to be acknowledged and respected



How things are changing

Feature	Former system	NDIS
Access criteria	Varies from state to state	Nationally consistent as set out in legislation
Choice and control	Varies from state to state - most people have little say over the supports they receive	Individual has control over the type and mix of supports, delivery and how their funding is managed
Level of assistance	Capped – people may be eligible but may spend years on waiting lists	Demand driven – people with disability get the support they need, when they need it, to make progress towards their goals
Funding	Multiple programs within and across governments	Single pool of government funding administered by NDIA

The roll out of the NDIS in Australia

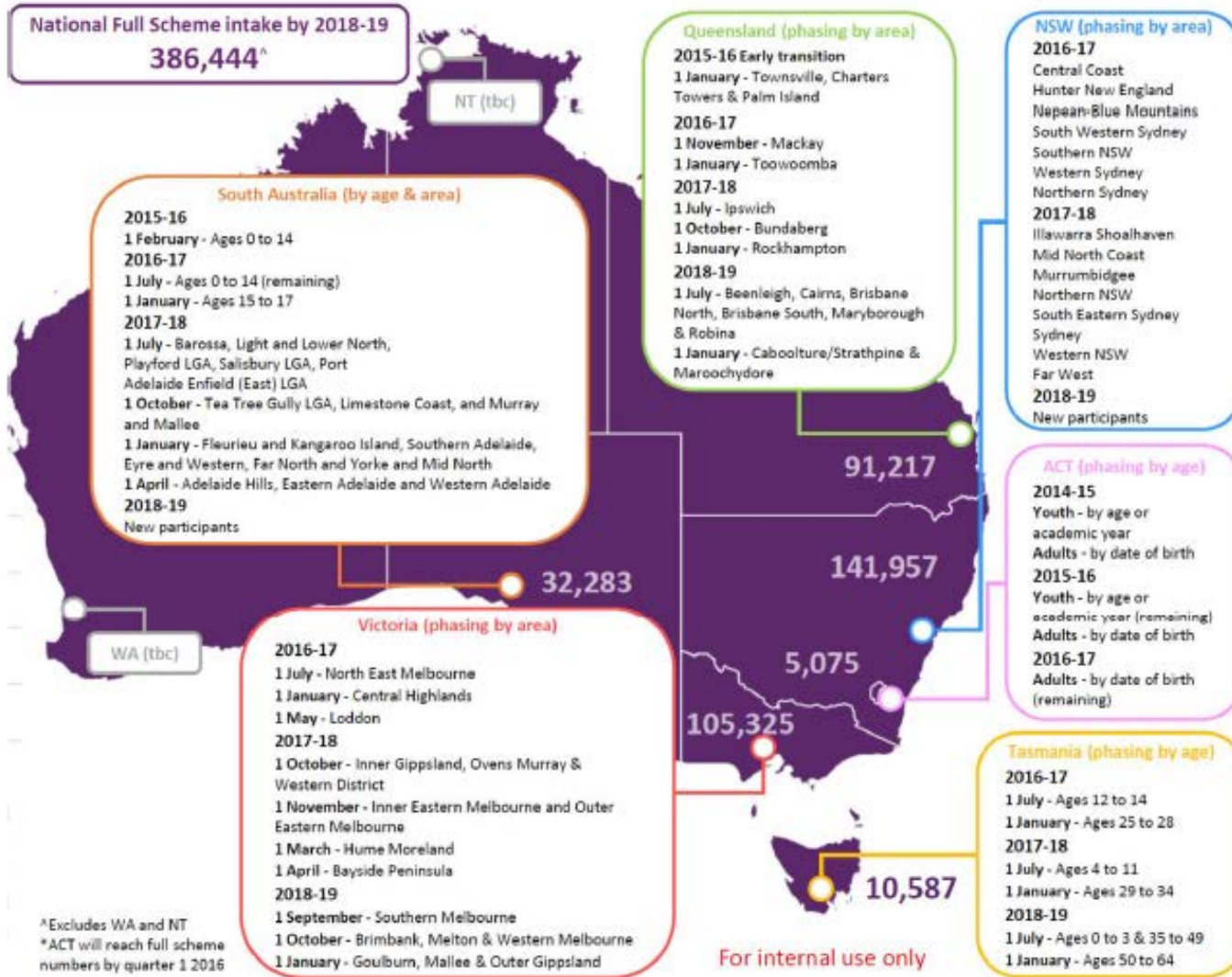


- The NDIS will be made available progressively across Australia over the next three years.
- Different arrangements apply in each State e.g. the first groups transitioning to NDIS in NSW are those from the current NSW Government programs - people living in large residential centres, group homes, hostels and those receiving high level in-home support.
- By July 2019, it is estimated that 460000 people will transition to the NDIS.
- In SA the roll out is first by age group up to 17 years (June 2017) followed by regional transitions to June 2018
- Importantly State/Territory Government funded clients transition ahead of new participants

NDIS Full Scheme roll out



March 2016



^aExcludes WA and NT
^{*}ACT will reach full scheme numbers by quarter 1 2016

Accessing the NDIS

- People with disability who meet the access requirements will become participants
- People with disability enter the NDIS through multiple channels
- There will be a gradual intake of participants around Australia



Disability requirements

To access assistance from the NDIS a person must have permanent disability which has a significant impact on everyday life and on their ability to participate in the community, and will mean they will need ongoing supports.



Early intervention requirements



Early intervention is for both children and adults.

To meet the early intervention requirements a person must have an impairment that is, *or is likely to be*, permanent.



AND

There is evidence that receiving supports now (early interventions) will help:

- Reduce the level of support needed, now and in the future **OR**
- Assist their family and carer to keep providing support

Early Childhood Early Intervention Approach

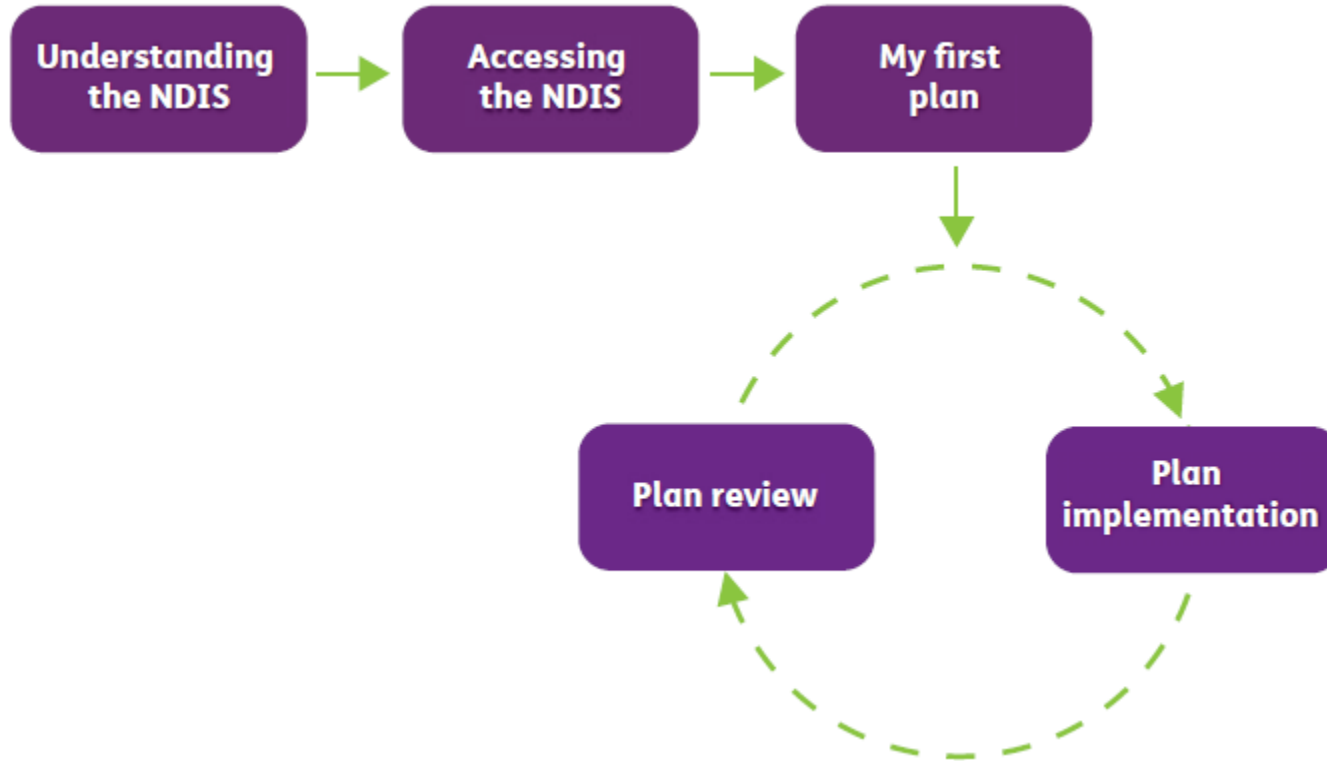


- Will help children with developmental delay or disability and their families achieve better long-term outcomes through support services in their local community, regardless of diagnosis.
- Provide timely, comprehensive and well-integrated early intervention support for children and their families.

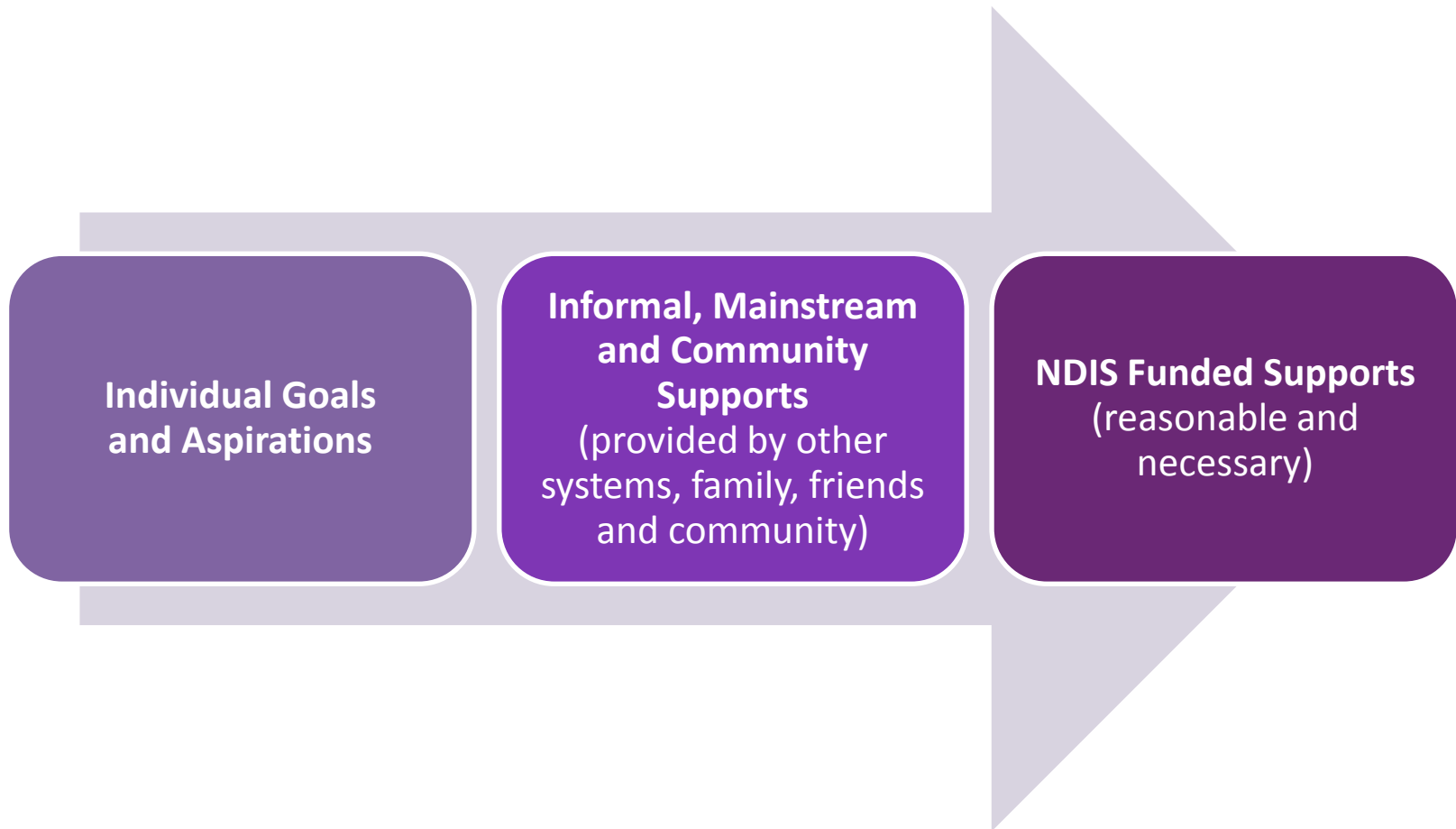


- Families will work with existing early childhood intervention service providers, who will act as an NDIS access partner.
- Currently being implemented in Nepean Blue Mountains for children under six.
- The approach will be rolled out nationally in line with Bilateral Agreements.

Participant Pathway



NDIS plans are individual



Funded supports

Funded supports must:

- Assist the participant to **pursue the goals objectives and aspirations**
- Assist the participant's **social and economic participation**
- Represent **value for money**
- Be, or likely to be, **effective and beneficial** for the participant
- Takes into account of what is **reasonable to expect families, carers, informal networks** and the community to provide
- Be **appropriate for the NDIS to fund** or provide

What NDIS will not fund supports:

- Not related to the participant's disability
- Related to day to day living costs
- Likely to cause harm to the participant or others

NDIS and the Health System

The NDIS will fund supports that help a participant to manage ongoing functional impairment that results from their disability, which includes:

- Supports that enable participants to undertake activities of daily living
- Non-clinical supports
- Aids and equipment
- Some exceptions – nursing care that is integrally linked to care and support

The Health System is responsible for assisting participants with clinical and medical treatment:

- Diagnosis and clinical treatment of health conditions (including ongoing or chronic)
- All supports directly related to maintaining or improving health status
- Rehabilitation and support after a medical or surgical event
- Medications and pharmaceuticals

Local Area Coordination

- Local Area Coordinators (LACs) will support participants and their families to join in and contribute to the life of their community and assist with the planning process, plan implementation and community participation.
- The NDIA has partnered with different organisations in different States to deliver NSW LAC services during transition from January 2016 – 30 June 2018.
- LACs will support participants through all steps on the pathway, except access.
- LACs will assist most participants transition to the NDIS, except where NDIA staff deliver this service directly for clients with complex needs.
- Most participants will also have an LAC assist with plan implementation, others may need more frequent and funded support coordination.

What happens next?

- This is the start of an important journey.
- The Commonwealth and State and Territory governments and the NDIA are working together to roll out the NDIS.
- People currently receiving government services will continue to receive them until they start their NDIS plan.
- The Commonwealth and State governments and the other organisations helping to deliver the NDIS will contact people transitioning to the NDIS with more information specific to them.

Questions?

Visit: www.ndis.gov.au/NSW

Phone: 1800 800 110

Email: enquiries@ndis.gov.au



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National Disability Insurance Scheme, adult participants with intellectual disability, adult physicians, hospital and health

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SHAID* Clinic, Calvary Hospital, Hobart, Tasmania
**Specialised Healthcare for Adults with Intellectual Disability*

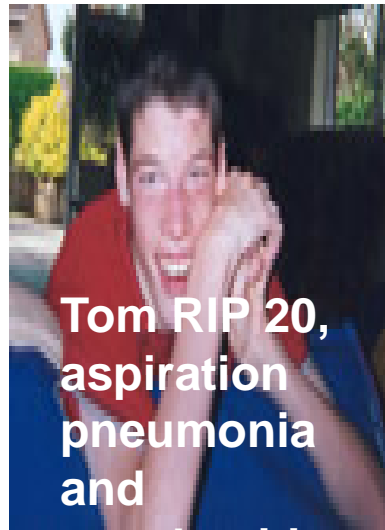
The Problem- Death by Indifference



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Ted, RIP 61 at home, after discharge from hospital



Tom RIP 20, aspiration pneumonia and severe pain



Mark, RIP 30 fractured leg, pneumonia, multiple readmissions severe pain



Warren RIP 25 ruptured appendix, not recognized



Martin RIP 43, stroke, not treated



Emma, RIP 26, cancer, not treated

from Mencap Report



NDIS operational guidelines on health

*Core NDIS for adult participants with intellectual disability: Goals and aspirations of the individual
re accommodation, respite, home mods, life skills, further education, day service, open or supported employment, community access, activities of daily living*



Operational guidelines - planning and assessment - supports in the plan-interface with health

Yes, fundable in NDIS plan

- Maintenance support from support workers while accessing health services (including hospitals) when that support relates to the participant's general and usual functional impairment
- Help with transport, making appts
- Support from allied health professionals for specialised tasks not able to be undertaken by support worker and related to usual functional impairment
- Training of NDIS funded support staff by nurses or allied health professional on a participant's individual needs

No, not fundable in NDIS plan

- Payment to health professionals for provision of acute, sub acute, post acute and chronic healthcare, including rehabilitation, preventive care
- Health funds, medications, temporary aids, dental care



First proposal

What adult patients with intellectual disability, in particular NDIS participants, and their carers, families, support services can reasonably expect from their adult health systems and adult RACP clinicians

Disability expectations of health



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- the presence of a specialised health service for adults with intellectual disability by physicians
 - knowledgeable about biopsychosocial setting
 - outpatients and consultation to colleagues' patients
 - willingness to make reasonable adjustments to usual education, point of communication with disability, within generic services
- robust and embedded disability awareness
- knowledge about the NDIS, how to engage, sort out health logistics
- a commitment with work with NDIS participant's/patient's family and funded support workers on health
- hospital policies, procedures, physical, attitudinal barriers, quality assurance, complaints, consent, accreditation wrt disability values, be fiscally responsible for the health services not funded by NDIS/optimize current resources, act on the urgency of the requirement



Second proposal

What the RACP adult clinicians and hospital systems can reasonably expect from the disability sector, the person's NDIS funded support services, in order to provide optimal healthcare for NDIS participants

Health expectations of disability



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- accept the relevance of health to facilitation of NDIS participant to participate in mainstream services and activities
- understand the algorithm of health assessment -history about the person, skills, communication behaviour, home, work, what went on leading to the event, the background medical history, medications, allergies, social history, presenting complaint, examination, tests, making diagnoses and management plans and reviews
- accept that the presence of even mild intellectual disability can very much impair the ability to provide optimal medical care by doctors
- acknowledge fundamental importance of the role of usual disability support in successful healthcare provision and access, and fund this
- organised, motivated and willing with respect to at home healthcare, emergency health plan, quality assurance, accreditation,
- be prepared to show graded assertiveness
- work with health to sort out NDIS-health engagement and planning



Third proposal

*A mechanism for NDIA and RACP engagement
big picture, small picture*

NDIA-RACP Big picture



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- start relationship between NDIA and a body of RACP clinicians: national, state level, regional, local level involving National Disability Services and consumer bodies..ongoing...
- conceptual agreement comprising acknowledgement and support the role for each body plays in contributing the best outcome in life for the NDIS participant
- health seeking advice on disability values and how to teach, and incorporate them in hospital policies and protocols
- NDIA-RACP standards on health accreditations for service providers, and disability accreditation for hospitals, RACP training programs, policies
- refine draft proposals of expectations from each other
- common commitment for integrity on funding allocation and accepting fair share of responsibility

NDIA-RACP Small picture



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- NDIS guide for physicians
- working out a process of how we talk and work- NDIS participant, their planner and physician
 - how does the adult clinician communicate with their patient's NDIS planner on anticipated relevant health issues for their patients who require health support because of their communication or behavioural problems
 - consideration of an automatic section on "health supports" in every individual NDIS participant planning process
 - a individual hospital resources to assist with disability supports requirement, and checklist for what disability supports should be able to expect
 - ensure resources not duplicated



Thank you



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NDIS in a land area three times the size of Britain

Dr Nigel Stewart





- SA. 900,000 sq mms. My region 85-90%
- ~ 100,000 people
- ~28% less than 15
- Strong Aboriginal peoples
- Industrial
- Agriculture
- Pastoral



- Family
- Great nurses and secretarial teams
- 3 other paed
- 2 registrars
- Support from local and regional admin
- University support
- Community



- ☺☐ Recognition of CP, speech, sensory, and intellectual
- 👉 Foetal alcohol syndrome
- 👉 ? ADHD
- 👉 ?autism



- 5 YEARS AGO
- Physio/ speech/OT/dietician/social work
- Childhood health teams
- Early intervention
- 1x private Ed psychologist
- Minimal private
- CDU/NOVITA/ad hoc specialist services
- Co-ordinated care, standardized at a minimum level.



- Disability co-ordinator
- Guidance officers
- Behavioural advisors
- Consultative speech
- CAMHS
- Local workers/ child psychiatry

- Families SA

Currently



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- Limited child health-initial assessments, await NDIA
- Private speech x7, 1 psyche, others growing
- Limited CDU
- 👍 specialist services, NOVITA weekly
- EDUCATION
- 😊 Re- organized and reduced- again!
- CAMHS
- 😞 New model of care, again! Narrower focus of service, more short term

- 0-13 trial
- Early intervention/ functional assessment.....diagnosis
- Adelaide based- as my state is
- Planning/ co-ordination/ services
- Client centered/ parent centered
- 6+ months planning,3-6 months services
- 💰 price, bands,high floor price
- Relentless review, be autocratic, sorry beaurocratic
- Inexperienced
- 😞 No professional partnership/ input
- 🐱 destroyed co-ordination
- 😞blaming professionals



- 👉 Improving throughput
- 👉 Improving professional/ parental communication and coordination
- 👉 address cost issues
- 👉 State abdicating responsibility
- 👉 increase professional expertise and access within NDIA
- 👉 incorporate multi-D, use case conferencing
- 😊😊 professional reference group
- 😞 improve access and options for disadvantaged

The future



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- Make NDIA work- expertise, money





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Dr Michael Bennett
Rehabilitation Physician
Barwon Health Geelong

Building the plane whilst flying it:
Barwon Health/McKellar Centre's test flight of the NDIS





- Key issues arising during our trial period
 - For the service
 - For the client
- Inpatient pathway and advice





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100 Subacute beds
Neuro, trauma, orthopaedic, GEM, amputee,
palliative care



Majority/3rd world case study (?)

-sabbatical 3 years ago



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- 32yo man with moderately severe ABI
- 3 weeks acute care/rehab
- Discharged after 3 weeks to family - PEG tube, IDC, 2 person heavy transfer, living in small unit up 3 flights of stairs
- Minimal assist from local nurses
- Family expected to hire cheap unskilled labor to provide care





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NDIS client Geelong

- Quadriparetic MS, 40yo, home alone
- 2 Carers 5x/day +prn for toileting
- Respite
- Holiday
- Hydrotherapy
- Taxi transport
- Ceiling tracking hoist etc etc



Universal access to assistance for people with disability is to be valued, lauded and supported !



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- Launched July 2013
 - Launch period to June 30 2016
- 4 initial sites
 - **Barwon – under 65yo**
 - Hunter area NSW- under 65yo
 - Tasmania – 15-24yo
 - SA – under 6yo





Key issues from our experience

- Trust
- Time
- Talking (Communication)



Trust



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- Prognosticating
- Planning
- Providing/Paying



Prognosticating

When is it '***permanent***'

When is it '***significant***'

- *'How do we know what residual deficit, if any, someone with stroke will have – get back to us in about 12 months when we know it's 'permanent'*
- Ditto for MS, Guillain Barre
- I'm assured this has been rectified, but prognostication by the caring team can still be a contested issue



Planning

- Skilled and experienced allied health will be planning not only for now but the future - which may ultimately save costs and certainly help adaptation
 - NDIS currently planning '*for current needs*'



Providing/Paying

- Wisdom of Solomon to decide what is 'reasonable' and 'necessary' uninfluenced by cost
- Long term provision may ultimately save costs
- Expertise of providers
 - Support coordinators - variable knowledge of disability?
 - Private allied health ? not neuro trained
- Appeals process - same person!



Time



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- 28 days from application to acceptance decision (average LOS stroke rehab = 30 days)
- Writing up of care plan
- Approval of care plan
- Possibly contesting costs of care plan
 - *‘Please quote for cheaper taps/tiles’*
- Costing decisions bounce b/w SWEP and NDIS
- Hiring and training carers
- For outpatients, rehab staff have the skill for planning but is it their ‘job’ or NDIA’s?



Talking



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Talking (communication)

- Client likely to have private allied health, public allied health, support coordinator, many other health care professionals
- Need named contact in NDIA asap
- NDIA prefers to liaise directly with client





Talking (communication)

- Advocacy
 - Need good IT skills for online information
 - Client and carers/family need good health literacy and a knowledge of all options, not just those offered
 - NDIA not paying for advocates



Inpatient pathway



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Guide to typical pathway for *inpatient*

- Minimum of 28 days from ***application*** to decision if accepted or not
 - **Advice – start early!**
- If ***accepted***, support co-ordinator should be appointed for that patient
 - **Advice – ensure you have a named contact!**
 - **Consider named contact for health service**
 - **Support co-ordinator will meet with pt/family to set *goals***
 - **Advice – suggest that staff assist with goal setting**





Guide to typical pathway for *inpatient*

- NDIS will then ask for a ***care plan*** from treating team/allied health eg care hours, equipment needs, home mods
- **Advice – develop a proforma for this for your service asap – it is very time consuming**
 - Early home/site visit to flag necessary home mods





Guide to typical pathway for *inpatient*

- NDIS may then question aspects of care plan, particularly equipment needs and mods costing
 - Our OT's have been increasingly asked to not only review costings, but to quote for 'cheaper tiles', 'cheaper taps' etc – meaning OT's spend hours doing building costings and quotes





Guide to typical pathway for *inpatient*

- If/when care plan/equipment needs/home mods are agreed to, mods need to be implemented, carers hired, carers trained, equipment sourced
 - Experience –
 - Recruiting and training carers can be difficult and time consuming
 - Extensive home mods can be very time consuming
 - The ‘rehab’ may well come to an end before carers or mods are in place
 - Where does the client go while they wait for carers/housing?





Issues affecting inpatient/neuro rehab clientele

- Where does the young person go, if anywhere, in the interim?
 - NDIS won't pay for interim accommodation
 - Transitional care programmes are wary of accepting without a defined discharge destination, particularly if new eg wheelchair accessible accommodation is being sought in the community
 - If interim residential care is found, usually in a NH type environment, can the NDIS be relied upon to continue to work to get that person out of residential care?





Issues affecting inpatient/neuro rehab clientele

- Experience of Hunter service NSW
 - Young person admitted to resi care with assurance of move to community later – ultimately that commitment was withdrawn.
 - So Hunter keep all their NDIS pt's in rehab until the plan is seen to fruition, including equipment provision, meaning their LOS for NDIS stroke was 160 days (cf. benchmark 30)





The Perils of Building a Plane While Flying It



And they are all too often accustomed to being first on board,
last off and.....



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Having no choice but to take a leap of faith in the 'system'





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Thank you

Panel Discussion – Questions Welcome

