



SUMMARY REPORT

Children, their Families and NDIS Forum

Thursday 29 November 2012 10:00 am – 1:00 pm

**Prepared for the Joint Forum Partners - National Disability Services,
Centre for Excellence in Child and Family Welfare, Early Childhood
Intervention Australia (Victorian Chapter)**



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Forum Background

In partnership, the National Disability Services, Centre for Excellence in Child and Family Welfare and Early Childhood Intervention Australian Victorian Chapter joined to coordinate a three hour forum scheduled on Thursday 29 November 2012 at Shannon Park, Geelong.

The aim of the forum was to engage representatives from Early Childhood Intervention services, children's disability services operating in the Barwon Region, relevant government staff and other stakeholders to:

- Consider the range of issues arising in relation to services for children and their families in the context of the NDIS
- Identify areas of concern; areas requiring further investigation, and valuable aspects of the existing service system which could be incorporated into NDIS
- Contribute to key recommendations compiled from Forum feedback and provide to NDIA, government, peak bodies and service providers to further inform relevant development work

Panel Presentations

James O'Brien, A/State Manager, NDS offered the formal welcome to country and to all attendees.

A panel of five keynote speakers was invited to each offer '5 minute Thought Starters' to the representatives attending on the day.

Panel members included:

1. Mary Hawkins, Branch Manager, NDIS Launch Transition Agency
2. Philippa Angley, National Policy Manager, National Disability Services
3. Lauren Matthews, EO, Early Childhood Intervention Australia, Victorian Chapter
4. Michelle Burrell, Manager, Strategic Projects and Policy Unit, Victorian Equal Opportunity and Human Rights Commission
5. Elizabeth McGarry, CEO, Association for Children with a Disability

1. Mary Hawkins - Branch Manager, NDIS Launch Transition Agency

- Her team looking at Quality Frameworks, mechanisms and service providers
- Background in rehabilitation counselling, compensation
- Concept of co-design
- Agency will proactively seeking input on this approach of co-design
- COAG developed principles which Agency has to test any policy against
 - Insurance Principles
 - Reasonable & necessary supports
 - Choice & Control -person
 - Consistent approach to eligibility
 - Equity of Access
 - Transition - continuity of support so current recipients are not disadvantaged



- The NDIS Launch Transition Agency is also working on the principle - tell your story once - only requiring specialist assessment where necessary

2. Philippa Angley, National Policy Manager, NDS

From National Consultation with members - 3 points from looking at Better Start and HCWA (Helping Children with Autism program)

Choice:

- NDS supports but its not without challenges - e.g. families selecting therapy options which others don't agree with
- Issue of how to support families to make best, informed choices

Evidence:

- Similar issue of therapies being chosen without real evidence to support efficacy
- How to build evidence base and what are the appropriate quality assurance options

Collaboration:

- Concern about decreasing collaboration between professionals within an individualized model
- Question of how NDIS could support collaboration in best interest of children

3. Lauren Matthews, CEO, Early Childhood Intervention Australia, Victorian Chapter

From Victorian Early Intervention program

- Work from strength based perspective
- Concern about NDIS being adult centric
- Will people on the ground have the knowledge of best practice in working with children and families?
- What will happen when child turns 6 - what will the residual or mainstream services offer?
- Where will early childhood intervention service fit within NDIS - will it be shifted to a disability service rather than universal/inclusive service?
- Concern that individualised focus will weaken emphasis on inclusion and universal approaches
- How to determine what best practice looks like?

4. Michelle Burrell, VEOHRC

Commission excited about service system being developed which can give effect to UN Convention in Victoria. This state has the advantage of the Charter of Human Rights. How can this influence service design?

- Need to consider best interest of children in context of broader human rights of child
- Themes from two research projects - certainty, choice, transitions
- Issue of young people and parents relinquishing young people to get into the adult system
- 'Reasonable and necessary' needs to be interpreted with a human rights lens
- Question of how to strike the balance of needs of families and need of individual child
- What does exercise of choice and control mean for children and young people?

5. Elizabeth McGarry, CEO, Association for Children with a Disability

- Concern that DSOs have 'dropped off the radar' in NDIS design
- View that DSO should be part of the Barwon launch
- Role of DSO with provision of information, engagement with universal services

- DSO to sit aside from disability sector and operate without conflict of interest - more than person centred approach - a holistic approach to 'keeping life on track' and connected to community rather than 'sucked into disability vortex'
- Need more attention to informal supports and avoid dependence on disability services
- Elizabeth read out a poem she had written - 'Life through the eyes of a child'
- NDIS - opportunity to 'have a great life'

Following on from the panel presentations, representatives were invited to engage in table discussion to address three key questions:

1. **What are your key issues in relation to children and families?**
2. **What do you want retained from the existing service system?**
3. **What issues require further exploration?**

Questions to the Panel

Q1. Experience of benefits of changing/supporting families rather than focus on therapies for children?

Answer - Mary Hawkins - We hope to gather evidence and develop good practice guidelines to publish

2. Sandy Morrison, CEO Glastonbury - How to deal with lack of evidence base to inform choice?

Answer - Mary Hawkins - Support people to try out/test different approaches/services

3. Michelle Burrell - How do we balance self-assessment and professional assessment, particularly where there are not services that work for certain cohorts - how to support innovation, development of models?

Answer - Mary Hawkins - There is provision for community development and piloting approaches.

Answer - Elizabeth McGarry - There are some examples in Victoria through ISPs that approaches have been tried for individuals (it is important that evidence requirements don't stop these innovations)

Answer - Philippa Angley - Can't walk away from need to develop evidence base for NDIS because of insurance model and requirement to show value for money. Need to develop evidence base for early intervention

4. John Foster, Noah's Arc - Concern about use of old notions of evidence; modern approach to evidence-based practice takes into account all perspectives of what is working, particularly families' perspectives. Should we be concerned that we don't revert to old scientific notions of evidence? How can we also retain focus on learning and development and not overly focus on 'care'?

Answer - Mary Hawkins - If that happens we would have failed. Focus from Productivity Commission was on participation and NDIS is about removing barriers

Additional comments

- Lauren Matthews - concern that segregated services may be easier to purchase, and universal services abrogate their responsibilities to inclusion)

- Elizabeth McGarry - Concern that if parents get choice of spending dollars on therapy or on planning or how they can stay connected to community and universal services - parents will more likely choose therapies for their child.
- Lauren Matthews - Need to better about selling model of key workers, planning, integration
- Michelle Burrell - NDIS can be transformative as a system - for this to happen need to transform the other parts of the universal systems

5. Annie O'Loughlin, Department of Education - Need to acknowledge the specialisation of early childhood sector in the launch. What will community and sector development look like in the launch?

Answer - Mary Hawkins - Will look different in different areas. Focus on how to access universal, mainstream services; looking at how to work with community to make more accessible; there is no blueprint for this.

Lauren Matthews - Need to look at principles of universal design

6. Tania Curlis, Carers Victoria - How to keep universal services accountable for accessibility for children with a disability. Issue of Better Start program of families having issues of what is available when child turns 7 - e.g. can get funding for therapy but can't get funding for car seat to transport child. Funding for a car may be more effective for community access than other uses of funding.

Forum Attendance

A total of 38 people attended including representatives from children and family, and disability organisations; Department of Education and Early Childhood Development (DEECD); Department of Human Services, the NDIS Launch Transition Agency, academia, peak body and advocacy organisations.

Listing of Organisations represented at the Forum

ECIA	National Disability Services	Yooralla
Association for Children with a Disability	Victorian Disability Services Commission	Kids Plus
NDIA Launch Agency	Office of the Public Advocate	Bethany
Victorian Human Rights Commission	SCOPE	Glastonbury
MacKillop Family Services	Gateways Support Services	Noah's Ark
Carer's Victoria	Municipal Association Victoria	Barwon Health
DEECD	Department of Human Services	Centre for Community Child Health

Attendees also included:

- Colleen Pearce, Public Advocate, Office of Public Advocate
- Tim Moore, Senior Research Fellow, Centre for Community Child Health (Royal Children's Hospital)
- Lyn Barr, Deputy Commissioner, Disability Services Commission

Q 1: Key issues in relation to children and families

Key Themes Emerging

1. Empowering families

- Helping families navigate a complex system/advocacy
- Need to focus on family's supports as well as supports for individuals
- Best interests verses self determination – balance between support, inclusion and other needs as well as therapy
- Education, informed choices, empowered families
- wants for their child – a focus on changing the child will lead to focus on individual
- What are parents informed about?
- How does family centered practice fit in? New parents required to make choices but not fully informed – is irresponsible
- Families already burdened enough
- Concern about supports provided to self managers of money
- Need good engagement with families
- Need to specify the process of engagement and information provision that protect families
- How do we educate families on their choices; on services available (informed choice)
- Family support needs to be included in both the assessment and the planning processes – have family support as an automatic component

2. Funding

- Discussion re what is funded; justification of why families are requesting a specific service
- Effectiveness of what is funded (esp. in early intervention sector) based on research and evaluation
- Under market system, provider can market package to families and may not relate to good practice and evidence
- Concern about potential of cost shifting for universal services to NDIS; especially kids 7 – 18 year olds

3. Impact on current collaborative practice and joined up service system

- Transition – early intervention to school; pediatric services to adult services – link between services; choices – having well informed choices; current school funding system – school chooses how funding is spent (is this family centered?); well supported early on but as child gets older and teenager aged 16 years old often left on their own, not supported into adulthood
- 7 years plus – families very concerned what happens/options/access when child turns 7 years (education options for families to know what options they have; education wise – what happens in education (holding educators to responsibilities of educating children)
- Lack of clarity around the transition process

- How will Disability Services Organisation (DSO)/local network work?
- Transition move– more between medical and disability models (education of pediatric medical community) - for new parents; moving out of hospital into community/ECI services; getting good support immediately; timing 'early'; at risk, suspected and at diagnosis
- Maintaining a holistic approach/perspective (not reverting back to treating the broken part)
- How are group programs going to work under NDIS? – recreation and school holiday program; 7-18 year olds
- Will need lots of information sharing across systems
- 'broken bits' – how the system addresses children with disability in care (foster and residential)
- Importance of agency collaboration – when just purchasing separate things – how would a family encourage the agencies to work together?

4. Universal services approach for children and families

- We risk losing our universal services approach to support for children and families – how can the NDIS ensure we don't move solely into a disability specific approach?
- Concern that universal services will refer over to NDIS instead of picking up services (need to maintain the focus and the funded obligation) of inclusion in universal services
- How do we ensure the NDIS engages with other agencies that may be working with vulnerable families (not disability specific agencies)
- Will the ECIS 'key worker' model limit choices for families? Needs to be an element of choice

5. Capacity building

- Essential that capacity building of the community occurs
- NDIS needs to support the building of community capacity and interagency coordination
- How do we educate and engage the broader community – 1:1 therapy; medical professionals (pediatricians, GPs)

6. Service Providers

- Better Start – limited access to registered providers – want access to other providers; maybe want access to usual providers, individual practices may find BS registration too daunting

7. Need for Safeguards

- How to manage the conflict in practice?
- Contentious interventions; how to protect/manage?
- Need much more development of safeguards – at present limited coverage for DSC and community visitors. Legislation won't contain safeguards – what are the standards especially when services are self managed and in private homes?

8. Quality

- Guidelines/quality accreditation/reasonable and appropriate
- How can families be sure of the quality of services they purchase?
- Need appropriate expertise in the Agency and LAC relating to children

- What quality controls are going to be put in place for private service providers?

9. Workforce

- Children's (particularly early childhood development) expertise required in Local Area Coordinator role
- Need **appropriate expertise** in the Agency and LAC relating to children
- Need to have people with knowledge and expertise to support the family appropriately – to really know them and to support them to make decisions around what they need/want to reflect where the child/family is at that time

10. Outcomes

- Will NDIS look at the outcomes for the child or the outcomes for the family?
- Family support case worker – currently getting care management under an individual support plan (ISP) very difficult to get
- Outcomes framework – should reflect social expectations for all children and what family
- We lack a **framework for outcomes** – this relates to what we look for re evidence

Q 2: Features of the existing service system that must be retained

1. Evidence Base

- Retain the rich evidence base that we have
 - Who has relationships with the family
 - Adaptation around having a child with a disability
 - Need a trusting relationship with one key person/worker
 - Hard to move to a point where implementing strategies for family if not a good connection with family and deep understanding of the family (culture)
- The fact that we have Early Years Learning Framework – do you look at outcomes for all children or just children with disabilities
- Use of natural environments and the concept that therapy occurs in everyday life not just therapeutic environments

2. Joined up service/Current Universal Services Model

- Gains we have made in getting specialized service into universal services – how will new system allow you to provide the specialized support into universal services (i.e. child care, school, kindergartens)
- Commitment to supporting access to universal services e.g. 15 hours of kindergarten
- Early supports and universal services approach for families – a connected approach
- Universal services approach not just disability specific, eg. ECIS is currently located within the Department of Education and Early Childhood Development
- Specialisation of early childhood intervention

- Choices re support in natural environment – some centre based around family choice and integrated service; integration with family environment
- Sector drift – want to maintain specialist programs such as specialist Royal Children’s Hospital; Family Options for kids with high medical needs and in education
- Strengths based approach
- Collaborative approach between service providers; exists now and want retained
- Seamless service – parents identify that current model/system are not maintained when child enters schools; need to support around transitions
- We want levels of support in early years to be continued as they go beyond 7 years
- Don’t want reassessments at transition time to lead to loss of funding and supports
- Don’t want the system more complicated between state and federal systems
- The mix of skills and approaches/service delivery models that currently exist in early childhood services
- Child focus rather than ‘disability focus’ – and within the family community

3. Funding

- What will be rolled over from state money to NDIS – not clear
- Aspects of block funding should be kept – proportion of \$s at entry to receive service; advice; networking; capacity building
- Access for indigenous community – not economically viable
- Want to retain nonprofit sector in ECIS sector; supports social inclusion and development of social capital; current block funding supports this

4. Workforce

- Concerned significant shift in knowledge base as workers move from current services to NDIS
- Skills and knowledge in existing system – build on this – not lose the investment (already happening)
- Capacity to support professionals – collegiate; interdisciplinary team; want agencies in USA market model – results in worst problems of market system
- Key worker model – Family Services Coordination – having a team around the child coordinated by one person
- Experienced staff – specialization of EI staff – skills and knowledge

5. Family Empowerment/Support

- Parents feeling ‘lack of control’ in school system – parents feeling they are not being heard
- Early early timely support
- The time up front to listen to families – the crucial conversations with families
- Respect for families choices
- Dedicated advocacy for children and young people – poorly delivered in Victoria; very low service/capacity ; and advocacy for families
- Family support that is available through ECI now
 - need to build this into all therapists roles
 - have family services support plan – retain this
 - often families initially don’t know what is best support so a plan is useful

- Family Centred Practice – not about giving families everything they want; are equal partners with professionals and make ultimate decision
- Want to avoid families feeling they have wasted their money
- EI job is to empower the parent so parent can start empowering child
- Skills learned early on are needed right through
- ECI could offer this as their offering
- Commonwealth should only fund things that will contribute to this long term outcome
- Family focus – ECIS service system
- Natural environments – routines based – getting workers out into communities; build the capacity of the family within their daily routine and resources
- Ability for families to raise issues and have an independent complaint resolution process

6. Rural Access

- Access to services in rural/remote areas – will these families have ‘choice’?

Q 3: Issues requiring further exploration

1. NDIS – Entry, Access and Eligibility

- Entry into the NDIS – how many people can realistically go on line
- Tell the story once – how does this actually work?
- Multiple entry points – how many are ‘soft’ and how many are hard?
- Existing packages/services working with NDIS; what is model – what’s in and what’s out (Better Start; KISS; ISP; flexible support; SWEP); NDIS interaction with education/education funding
- How is it going to work – what’s the vision; what is in and what is out?
- Clients – how will they automatically be part of the launch or do they have a choice?
- Eligibility – families that don’t attend services; children who are yet to receive a diagnosis; who is out there that might be eligible?
- The need/development of a residual service system.

2. Joined up/Universal service Model

- How can NDIS be structured so it does not have a bias towards disability specific supports?
- How can we ensure a focus on the early childhood supports is maintained? What measures will be used? Timelines for review
- Intersection between NDIS and the universal service sector – relationship with families and role of families in making and being provided with full choice
- Connection with other mainstream services such as AOD; Mental Health; CP etc
- How will the services intersect – what will be education verses health?
- Explore universal design principles
- Opt in for additional support at key transitions/problems (both children and families)
 - Proactive preparation before, not during/after wherever possible

- How to ensure families are given the support they need to understand the process and understand the services available?
- Coordination of services
- Services for kids 7-18 year of age
- Support for people not in the NDIS – the need for a residual / universal service system.

3. Funding and Market Model

- Market places – developing these in good frameworks round them i.e. Early Years Learning Framework; need for clearer outcomes
- Dissolving of organizations – whole lot of private pediatricians
- Level of funding – will focus on family be lost?
- Benchmarking of costs of services
- Funds/funding of the NDIS
- Commonwealth and state relationships – risk of cost shifting
- Resources – cost of service verses NDIS pricing; impact of potential gaps – choices for families who cannot afford gaps; how to price ‘advice and support’
- Choices i.e. natural (more \$s) verses centre based (less \$s); key worker verses team or separate services
- Funding – proposed 25% rollout – what will this mean for services already being provided by 1st January 2013; 25% less budget from 1st July – yet no new clients until January 2014
- Will there be flexibility in the funding to ensure families can get what they need and not be given what guidelines determine they should have?

4. Accountability and Safeguards

Accountability of Finances and administration

- Safeguards – legislation doesn’t address this; but NDIS Launch Agency is looking at this issue; quality assurance will relate to potential level of risk; initially NDIS will adopt whatever safeguards states have in place; complaints will come to Agency and DSC and DHS; safeguards also being addressed in multilateral agreements; price checks etc covered in terms and conditions; need to decide who is allowed to self manage funding? Will be a reviewable decision
- ISP – accountability of what they do with their money – who carries the burden?; auditing; financial accountability; safeguarding and administration; protection measures and complaints
- NDIS – regulation around ‘accountability of the money; protection measures and complaints
- Who is putting in place the checks and balances around service providers?
- Who do we ensure that families are listened to as a matter of course – should not have to pay for this
- Service/fee structure guidelines – to be available to families realistically set base and ceiling costs

Monitoring

- How are we going to monitor these services; will there be guidelines?
- What service systems will exist for critical incident reporting – whose responsibility; response rate; medication errors – monitoring?
- What are we measuring to get the baseline figures?

- How are we going to record data – input activity against funding

Quality

- How do you monitor and check service providers re quality?
- How will we ensure that services are registered?
- What about the frameworks ; we lack a framework to inform what government will fund re early intervention
- Quality accreditation

Complaints

- Improve complaints/advocacy systems
- Early Intervention burdened with individual complaints rather than larger issues i.e. exclusion from childcare

5. Marginalised Groups

- 'Cultural safety' within NDIS – i.e. Aboriginal/Torres Strait Island/CALD/marginalised groups
- Rural and regional families – multi mode (on line, phone) delivery of support – technology; face to face; resource for development and capacity to build
- CALD communities – interpreters- centrally/universally funded?

6. Workforce

- Look at the LAC/case coordinator role?
- Workplace – finding and retaining staff in the exiting sector and the potential new sector
- Qualifications and experience and training for local area coordinators
- Education of workforce – undergraduates and professional training
- Need expertise re early childhood on Agency staff
- Have we had anyone appointed to the state advisory committee/task force with an ECIS background?
- How do we retain staff?
- What measures are going to be put in place to secure peoples futures (workforce?)

Priority Issues

Each table was asked to identify the Top 3 issues that occupied their discussions. The following is the combined table feedback to each question:

Q1. What are your key issues in relation to children and families?

- How do we educate families in making informed choices? Tendency to focus on one and one therapies and advice from paediatricians
- Education of GPS and paediatricians in launch site
- Decision making on 'reasonable and necessary'
- Question of expertise/experience of those developing plans within the Agency
- Question of role of community education in NDIS
- How will role of transition into school - what will ECIS role be in NDIS - what happens if developmental delay still at 6 years
- Respite - question of group programs - how will these work with individualised funding?

- What quality controls will be put in for standalone therapists/private service providers?
- What happens when a child turns 7?
- How do we balance best interest and self-determination?
- Fear of losing universal services approach with focus
- Risk of focus on family support being lost in assessment and planning and shift to focus on individual therapies etc
- Need more focus on safeguards in system
- How will engagement of families work?
- Maintaining a holistic perspective
- How to address needs of children with a disability in foster care/out of home care

2. What do we want retained from existing service system?

- Family focus- in ECIS
- skilled staff (ECIS)
- ECIS embedded in education/developmental model
- 'Key worker' and strength-based approach - but need clarity of role of key worker and what it means; e.g. a coordinating role for family/main contact for family (need to clearly define role and purpose)
- Maintain collaboration in a competitive environment
- Supporting families in naturalistic environments and working within families' home
- Need tools and measure of family quality of life and impact of services provided
- Access to independent complaints resolution
- Current information - ECIS and DHS funded flexible packages will be rolled into NDIS; preschool officers, kindergarten inclusion service will stay with the States
- Concern of losing gains in universal service approach
- Broader planning approach to supporting families
- Specialist early intervention approaches
- Don't want to retain current system for 7-18 yr olds- i.e. cut off when a child turns 7
- Maintain non-profit sector and community inclusion approach
- Specialist programs such as Royal Children's Hospital program for children with high medical needs
- Maintain child and family focus - not adopt a disability focus
- Maintain evidence base
- Want to retain focus on relationship with family

3. What issues require further exploration?

- How is NDIS going to work - what happens to existing clients funded at 1 July 2013?
- How do we retain staff in transition?
- Has someone with ECIS experience been appointed to the State NDIS task force or one of the Commonwealth Advisory groups/panels? (Answer - No)
- How will 'practical design' funded projects inform launch sites?
- What system for reporting to NDIS (FOFMS? to be used? - Issue that not outcome based)

- Will there be base prices for charges for services- particularly for private providers
- What provision will there be for critical incident reporting and responding to incidents?
- How will we address needs of CALD/ATSI communities? How to identify people who are eligible who are not on DSR? Will they be included in the figure of 5,000?
- Funding for interpreters etc
- Cost of service compared to NDIS funding
- Choices between group and individual services
- Retention of skilled staff
- Checks and balances for service provision
- Retaining families' role in planning
- Workforce- issues that Commonwealth definition of allied health is different than in States
- Safeguards- registration, police checks - to how to ensure that the frameworks used by service support families in ways discussed at forum
- How will 'telling story once' work in practice?
- How will multiple hard and soft entry points to system work?

Final Comments

Colleen Pearce, Public Advocate Office of Public Advocate

- Safeguards

Tim Moore, Senior Research Fellow, Centre for Community Child Health

- Need clear statement of outcomes we are seeking
- Want kids to participate meaningfully; needs functional skills so need to equip kids environments to do this
- NDIS is a means to an end – need to be clear about this and needs to fund activities to achieve its ends - this thinking isn't happening

Lyn Barr, Deputy Commissioner, Disability Services Commission

- Need independent complaints system to help improve quality of services
- Want current safeguards retained including Critical Incidents Reporting

Recommendations

Recommendations to include:

- Focus on retaining what we value of the current system e.g. advocacy/lobbying
- Want to retain non-profit sector in ECIS sector and continued investment in non-profit sector development and NDIS preparedness;
- We support social inclusion and development of social capital (current block funding supports this)