Speech
Pathology
Australia

Hon Kevin Andrews MP
Chair
Joint Standing Committee on the National Disability Insurance Scheme
PO Box 6100
Parliament House
Canberra
ACT 2600

30 November 2018

Dear Mr Andrews

Re: Request for further information by the Joint Standing Committee on the NDIS at their hearing on 22 November 2018 regarding Assistive Technology

Thank you for the opportunity to provide the Committee with further details of relevant issues and evidence from our members and their clients' regarding their experience with the NDIS.

There are three main areas of concern we would like to highlight:

1. **Further issues regarding Augmentative and Alternative Communication (AAC) Assistive Technology (AT)**
- We feel it is essential that the NDIA ensures continued access to supports such as those provided by the former specialised equipment services including:
    - a 'one-stop' centre of support, providing access to AT Advisors who can offer independent advice as well as direct supports (i.e. assessment, training, set up and support for equipment trial, individualised set up of AT) and/or capacity building supports to participants, primary therapy providers and others
    - a 'library' system for AAC AT to provide participants with the ability to trial equipment, to ensure they are able to identify the best AAC AT solution for them
    - A centralised system for provision and/or connection with suppliers of AAC AT
    - Innovation and governance for provision of electronic AAC AT.

- These specialist equipment centres should accessible nationally. A co-design process, focused specifically on the different and additional aspects of provision of AAC AT and involving SPA and other stakeholders is urgently needed; to identify the systemic needs; plan for and develop the systems and structures to address these needs; safeguard the specialised equipment services still operating and support their continuation into the future. The impacts of the loss of the few remaining systems will be felt particularly by participants (and providers) in rural and remote areas.

- In addition to providing support to participants and families, these specialist equipment centres would have a number of other potential benefits including:
    - reducing the incidence of planners overruling practitioner decisions, as the accredited centres will, in effect, provide NDIA "approved" advice, which in turn will speed up the acquisition process, as well as decrease the number of costly and time wasting reviews and appeals
    - ensuring an individual has timely access to the most appropriate ACC AT device. This is particularly important for young children who benefit from early intervention and for people with a degenerative conditions
    - ensuring an individual has the most appropriate ACC AT device will also reduce equipment abandonment rates and has further cost saving potential in that a piece of equipment may be used for a number of years

- enabling recycling or refurbishment of certain equipment as appropriate, similar to the program currently running in NSW.

- It is the position of Speech Pathology Australia that working in the field of Augmentative and Alternative Communication (AAC) is within the scope of practice of speech pathologists. The AAC AT assessment process is multi-phased and multi-faceted and therefore speech pathologists may need to engage in activities to actively update their competencies in this area in light of the growing evidence base and technological developments that impact on the field. Continued engagement with professional development is one of the requirements for practising membership of Speech Pathology Australia.

- The Association is aware that practitioners need an understanding of specific design and access issues around AAC AT and device features when supporting the selection of an AAC AT solution that matches a participant's needs, abilities and communication participation goals. The Association supports a model similar to one employed by the Victorian State-wide Equipment Service which can offer the scaffolded supports whereby providers can develop the knowledge, skills and expertise about AAC AT, helping to build capacity in the sector as a whole.

- The Association acknowledges that members working in these roles would need to be able to demonstrate capacity in order to be able to offer these supports. The Association would request that it is invited to contribute to the design of a national system that adequately reflects the different and additional needs of the sector in the provision of AAC AT.

2. **The certification process for Early Childhood support**
- Members are expressing concerns regarding the current cost of registration under the Commission to deliver Early Childhood Supports (ECS). This cost is substantial, both financial and to the business in regards to time and productivity whilst several staff members are spending considerable hours preparing for the audit.

- Many members have not yet obtained quotes for audit, as they have until March 2019, but those who have ranged from $10,000 across the three years to $30,000. One of the quotes for $10,000 was for a speech pathologist who had only four NDIS clients. Several of the auditing bodies have 'closed their books' and are not providing quotes as they do not have capacity. Please see the attached example of quotes obtained by a registered provider for their audit (which included early childhood).

- There are only eight registered auditors, the majority are based in Queensland or NSW, with only one in Victoria, and none in any of the other states or territories. This is despite South Australia being one of the first states to roll out under the Commission. There are reports from our members of this disadvantaging providers in other states, or those who are rural and remote practitioners, as they have been asked to also pay additional costs for the auditor's travel and accommodation.

- There does not appear to be a delineation between large companies who may have formerly been delivering Early Childhood Intervention Services (ECIS) under state block funding, and small private providers who are looking to provide therapy supports to children under seven. A Commission representative reported in a meeting that they believed that it was only these larger organisations who would have the ECS supports allocated in plans, and that smaller allied health providers would be able to claim against the Therapeutic Supports item, including for children aged under seven. However, plans for children aged under six include only ECS support items.

- This demonstrates the lack of understanding of the sector, and implications of an additional and overly onerous registration process for providers who are already well regulated, either through AHPRA or as part of a self-regulating profession.

- The standards for ECS appear to have been developed assuming that all ECS will be provided using a key worker model previously employed by Early Childhood Intervention Services in NSW and Victoria. Sole providers, and small businesses may not be able to adopt this model due to their structure, and concerns have been raised by members who feel they may be penalised, even if they are acting according to the best practice guidelines (copy attached), simply because they do not have a multi-disciplinary team.

- Registration to provide Therapeutic Supports requires allied health providers (whose businesses are structured as individuals or partnerships) to complete a Verification process that is a replication of the existent regulatory requirements for practicing membership of Speech Pathology Australia. The only additional (and very appropriate) requirement is to demonstrate compliance in terms of the state based safeguarding checks such as Working with Children and Police checks.

- All businesses with an incorporated structure are required to undertake Certification against the twenty two standards within the core module, regardless of the supports they are registering to provide. This means that sole speech pathologists who are only providing Therapeutic Supports and required to fulfil the same demands, as large companies with a hundred employees who also provide home care support. Clearly there are very different risks for a provider of Therapeutic Supports, who may be an incorporated business, and another large business who may be providing supports to help people with disabilities (PWD) shower, or get in to bed at night.

- Registered providers in NSW and Victoria whom may have already undergone an audit (at their own cost) to be able to deliver ECS as part of their state based requirements are not having these audits recognised, and are still required to undergo this second audit, again at their own expense.

- The current discussion and report from members is that due to the points listed above, they are planning to de-register, or indicate that they will re-register, but then forgo audit and allow their registration to lapse, as they are unable to absorb those kinds of costs. This is particularly the case for smaller businesses, or sole providers who work part time, and those in areas without easy access to auditors. Some members have expressed concerns that the families that they work with will not be able to access other services, as they are not able to self-manage.

- The Association has grave concerns for market failure in the early childhood sector, where there will be a lack of providers, and therefore choice and control for families who are unable to self-manage. This will particularly affect the most vulnerable who may have disabilities themselves, are from CALD or low economic status backgrounds, or simply live in rural areas where their local provider is no longer able to provide services.

- It is unclear why the NDIA chose to identify the provision of allied health interventions to children aged under six as ECS, and therefore classify them under the high risk category. While it does require the provision of family centred services using strengths based approaches and including capacity building for communication partners and others, this is part of the provision of speech pathology services regardless of whether a child is over or under seven – and in fact, aside from the shift to person centred rather than family centred, it is the same for many adolescents and adults with disability.

3. Speech pathology supports for oral eating and drinking

- There is ongoing uncertainty and inconsistency regarding provision of speech pathology supports for functional assessment of oral eating and drinking and development of mealtime guidelines for PWD and oral eating and drinking difficulties.

- These supports have previously been provided by speech pathologists working in the disability sector, and in the early years of the NDIS, these supports were included in participant plans, however there are increasing incidences whereby planners are refusing to include them. The NDIA has posited that as a mealtime management plan is prepared by an allied health professional (e.g. a speech pathologist) to prevent a health condition such as aspiration pneumonia, the development of the plan is most appropriately supported by the health system – thereby 'medicalising' the entire process of eating and drinking.

- This is both a narrow and skewed representation of the role of speech pathologists in the provision of supports to PWD who experience difficulties with oral eating and drinking. Elimination or minimisation of the risk of choking and aspiration is an important aim, but there is a broader focus on enhancing participation in enjoyable, effective and safe mealtimes, at home and in other community settings, as part of living an ordinary life. Therefore, the assessment provided must also take into consideration not only the person's swallowing difficulties, but also other environmental factors.

- Speech Pathology Australia (SPA) asserts that the provision of a dynamic functional assessment of oral eating and drinking, development of recommendations, and provision and implementation of mealtime guidelines for people with disability is part of 'reasonable and necessary' supports and should be funded through the NDIS i.e. in participants' plans (based on COAG principles).

Further detail regarding speech pathology supports for oral eating and drinking and client case studies can be found in the attached documents.

Yours faithfully,

Gaenor Dixon,
National President

Attachments:
- Speech Pathology Australia briefing paper: Speech Pathology Supports for Oral Eating and Drinking
- Speech pathology Australia supplementary paper: Case Studies - NDIS position regarding funding of supports for Oral Eating and Drinking
- Case study- auditing costs
- National Guidelines: Best Practice in Early Childhood Intervention (ECIA 2016)

Speech Pathology Australia briefing paper: Speech Pathology Supports for Oral Eating and Drinking

Introduction and Context

There is current and continuing uncertainty regarding provision of speech pathology supports for functional assessment of oral eating and drinking and development of mealtime guidelines for people with disabilities (PWD) and oral eating and drinking difficulties.

These supports have previously been included in participant plans, however Speech Pathology Australia (SPA) is aware of a growing number of incidences over several months of Planners in NSW refusing to include them, and more recently in Victoria and elsewhere. These changes are apparently being implemented by the NDIS based on its position that they 'are best provided by health'.

This practice is creating significant risks for PWD and oral eating and drinking difficulties, including short and long-term health outcomes, and participation. These risks are arising in the context of:

- No agreed decision at a COAG level, and based on the Principles to Determine the Responsibilities of the NDIS and other service systems
- inconsistency regarding the inclusion of these supports services and products in NDIS Participant Plans.
- No or inconsistent information to Providers or Participants regarding this direction
- The lack of an alternative service system for delivery of these supports

The NDIA has posited that as a mealtime management plan is prepared by an allied health professional (speech pathologist) to prevent a health condition such as aspiration pneumonia, the development of the plan is most appropriately supported by the health system.

This is both a narrow and skewed representation of the role of speech pathologists in the provision of supports to PWD who experience difficulties with oral eating and drinking. Elimination or minimisation of the risk of choking and aspiration is an important aim, but there is a broader focus on enhancing participation in enjoyable, effective and safe mealtimes, at home and in other community settings, as part of living an ordinary life.

SPA agrees with the principle that the health system in Australia has an obligation and commitment to provide the same level and type of services to PWD as for any other Australian citizen. In this case, these include instrumental assessments of swallowing, and interventions in the acute and post-acute stages following identification of an acute need or deterioration in function.

SPA Recommendations

Provision of a dynamic functional assessment of oral eating and drinking, development of recommendations, and provision and implementation of mealtime guidelines for people with disability is part of 'reasonable and necessary' supports and should be funded through the NDIS i.e. in participant's plans. (Based on the COAG principles - see Appendix A)

SPA should be consulted (along with Dietitians Association of Australia and other relevant networks and alliances) to further refine the support role delineations for NDIA and mainstream health, as well as other sectors where direct support for mealtimes is provided e.g. education, childcare, community services etc.

Additional information and discussion

The purpose of this paper is to inform the application of the COAG principles to determine the responsibilities of the NDIS and other service systems.

Background

Eating and drinking has a core place in the lives and culture of all Australians. Along with everyday meals with family or peers, it is also a central part of celebrations and social get togethers. It is a pleasurable and social activity which is part of our everyday, ordinary lives; few Australians would think it an activity undertaken purely for the sake of their health and wellbeing. Early feeding plays an important role in the development of the parent/child relationship, and mealtimes are an important part of children's everyday routines, and for social, emotional and physical development. There is considerable research linking mealtime experiences with important lifelong social, emotional and health related outcomes

Speech pathologists provide supports associated with eating and drinking with four differing areas of clinical focus/goals:

Functional: supporting PWD with oral eating and drinking difficulties to have enjoyable, effective, and safe mealtimes, including through the provision of guidelines to those providing direct mealtime supports. The need for these supports is specific to people with disabilities who have oral eating and drinking difficulties i.e. other Australians do not require these supports for their functional involvement in eating and drinking.

Developmental: supporting skill development for children whose oral eating and drinking are delayed or disordered, and who have associated developmental disorders (such as Cerebral Palsy, Down Syndrome, Autism Spectrum Disorder)

'Resistant eaters' – supporting an increased range and amount of food and fluid intake for children and adults whose sensory disorders, oral-motor difficulties, food intolerances and even medical disorders such as reflux and/or behavioural issues (in the absence of any discernible physical or motor planning issues) lead to them having a limited range of foods that they will eat, which in turn often leads to them having inadequate nutritional intake.

Rehabilitative: supporting recovery of oral eating and drinking skills for people with an acquired dysphagia (e.g. resulting from stroke or surgery).

There is potential for PWD to require speech pathology supports for oral eating and drinking across more than one of these areas.

For the purpose of this paper, SPA has focused on the provision of Functional supports.

Functional Oral Eating and Drinking for PWD

PWD experience limitations and barriers to participation in the activity of eating and drinking due to body structure and function differences resulting from or associated with their disabilities. They are often reliant of direct supports (i.e. assistance from another person) at mealtimes.

These needs are additional to and qualitatively different from those of other populations who may experience health risks arising from dysphagia.

Oral eating and drinking difficulties are common in people with lifelong disability (e.g. Cerebral Palsy, or Down Syndrome) and can also occur as a result of acquired disabilities (such as Motor Neurone Disease or Stroke).

Recent studies have shown about 15% of people with lifelong disabilities require support to eat and drink and 8% of people known to disability services for people with lifelong disability have dysphagia.[1] It is

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[1] Guidance – swallowing difficulties.UK Government
https://www.gov.uk/government/publications/reasonable-adjustments-for-people-with-learning-disabilities/swallowing-difficulties-dysphagia

difficult to get an accurate estimation of the numbers of people with disabilities who have oral eating and drinking difficulties, but it is likely that any numbers will be an underestimate, as these difficulties often go undetected and are under-reported.

It is important to note that some PWD do not have any difficulty with the process of swallowing but may still experience barriers to the enjoyment and effectiveness of their meals. For these individuals, safety is clearly not an issue, and the sole focus of support is on enhancing the enjoyment and/or effectiveness of the mealtime.

Providers

Speech pathologists are key members of the multi-professional team (including Dietitians, Occupational Therapists, Physiotherapists, support workers), who provide solutions to enable persons with disabilities (PWD) to participate in the functional activity of oral eating and drinking, and experience an enhanced quality of life, as well as be safer.

They develop guidelines for those providing direct support (family, unpaid and paid supports), including information and strategies with the aim to support enjoyment (e.g. food preferences, preferred mealtime companions), effectiveness (duration of meals, when and how to offer food, how a person may signal hunger, sensory preferences) as well as safety (food and fluid texture, positioning during and after meals, amount of food offered per spoonful, provision of sips between mouthfuls).

Prior to the introduction of the NDIS, across all jurisdictions, most supports for functional participation in mealtimes for PWD were provided by speech pathologists in the disability sector. For the most part, these speech pathologists are now part of the NDIS provider market.

Instrumental Assessment of swallowing provided by Health

There are a range of instrumental assessments used to determine what is occurring during those parts of the swallowing process which cannot be visually observed. These include Video Fluoroscopic Swallow Study (VFSS), Modified Barium Swallow (MBS) and Fibre-optic Endoscopic Examination of Swallow (FEES). These require both complex and costly equipment, and expertise (in using the technology and interpreting the results) and are typically offered by tertiary health services.

In the case of PWD, they are typically not being used to determine the impact of an acute health incident and would be provided as part of an outpatient service. Instrumental assessment is usually requested where there has been some deterioration of function, and is not frequently required to inform the development of mealtime guidelines

Instrumental assessment of swallowing provides a 'snapshot' of a person's skills. It can provide 'baseline' information about how they are managing foods and fluids orally and strategies to ameliorate or eliminate aspiration and may also provide an objective measure of changed swallowing function.

There are limitations to their use, and they are not always necessary and are not sufficient to inform the development of mealtime guidelines to support enjoyable, effective and safe oral eating and drinking.

Dynamic Functional Assessment of Oral Eating and Drinking

To develop guidelines for the provision of direct supports during mealtimes by family or friends or paid workers, a dynamic assessment needs to be provided in the everyday environment of the PWD.
This includes observations of:
- *Body structure and function*: postural control, grasp and hand control, positioning, sensory abilities (vision, hearing), motor and sensory aspects of the structures involved in swallowing (lips, teeth, tongue, cheeks, soft palate, pharynx, larynx and oesophagus). Functions observed include locating, picking up and carrying food to the mouth, biting, containment of food and saliva in the mouth, chewing, management of food inside of the mouth including preparation of a bolus, initiation, speed and coordination of the swallowing process, including laryngeal elevation.

- *Activity:* What food is offered, how much is offered at a time, how is it offered, pace and duration of the meal, texture of food and fluids, order are foods offered in, opportunities to exercise choice and control in the meal, signals used to indicate preferences or satiation etc.
- *Contextual factors:* physical environment, seating, seating arrangements, lighting, smells, people present, behaviours, skills and attitude of the person providing direct supports etc. This may also include an exploration of policy or practice barriers impacting on mealtime participation.
- *Participation:* Interventions across all of the areas identified above aim to support both short and long term participation in mealtimes for PWD, including social, emotional and cultural aspects of oral eating and drinking.

Dynamic assessment allows for the trialling of strategies which may support the person's participation in mealtimes in the real context and in real time. For example, if a person becomes agitated during mealtimes and refuses food, there may be number of hypothesis about the reasons for this behaviour. In a dynamic assessment approach, hypotheses can be tested, and their impact assessed in real time e.g. agitation is due to being moved from one activity to another. The intervention may be trialling providing a touch cue 2 minutes before going into the dining room and observing whether that reduces the level and/or frequency of the agitation.

This assessment of functional oral eating and drinking provides the basis for the development and implementation of recommendations for strategies and techniques which could be put in place to provide for enjoyable, effective and safe mealtime, including information and training for those providing direct supports.

As part of person centred capacity building approaches, the participant, or their guardian needs to be informed of what is being recommended, alternative options, the evidence underpinning the recommendations and the potential consequences of their choices and decision, to enable an informed choice.

The greed recommendations then form the basis of the mealtime guidelines, based on the participant choices, and recognising dignity of risk as well as the rights and responsibilities of paid workers.

Those who are providing direct supports at mealtimes require access to information and training, both 'generic' (i.e. about eating and drinking and swallowing, and including experiential learning) and in many cases, in relation to the specific and individual needs of the person they are supporting.

It's worth noting a parallel for provision of NDIS funding for a functional assessment. The **functional** behaviour assessment occurs in the person's own environment and identifies risks/triggers to the participant (and others). The professional that undertakes the functional behaviour assessment also prepares the behaviour support plan (see reference from the Price Guide on page 61 below), to help the person build capacity to live an ordinary life, as it's not reasonable or practical for another professional to propose interventions for someone they have not met.

Support Item	Support Item Ref No.	Description
Specialist behavioural intervention support	11_022_0110_7_3	Highly specialised intensive support interventions to address significantly harmful or persistent behaviours of concern. Development of behaviour support plans that temporarily use restrictive practices, with intention to minimise use of these practices.

The same principles should apply for a **functional** assessment for a person with oral eating or drinking difficulties.

System needs

Best practice for the ethical provision of speech pathology interventions for people with disabilities who have oral eating and drinking difficulties requires:

o responsive and timely service access

- o a workforce with the necessary competencies
- o that the same allied health professional/s who undertakes the functional assessment to
  1) also develop the mealtime guidelines AND
  2) provide the information and training to the paid and natural supports who are
  providing the direct support at mealtimes.[2] It is neither appropriate, efficient, or ethical for the speech pathologist 'implementing' the mealtime guidelines to do so without having undertaken the functional assessment of the individual.
- o the involvement of the natural or paid support person/s to contribute information about the person with disabilities (PWD) abilities, preferences, and opportunities to increase choice and control in that context etc.
- o the inclusion of a dynamic assessment of the functional oral eating and drinking skills of an individual in at least one of their everyday environments.
- o a system for reporting and responding to near misses and critical incidents related to oral eating and drinking
- o acknowledgment of the expressed and observed preferences of the individual and supporting informed consent whilst advocating for a person's right to dignity of risk[3]
- o understanding and advocating in relation to 'duty of care' responsibilities for the allied health professionals, direct support workers, and organisations providing paid supports.

It should also:
- o Support the ability to work collaboratively with the natural and paid supports in a person's life
- o Be provided using collaborative, person centred, and capacity building approaches
- o Be provided in the context of a system with policies, procedures, and work instructions which support and facilitate the provision of high quality supports, including mechanisms to support identification of need, referral pathways, processes for review, continuity of care etc.
- o Provide support for integrated and coordinated multi-professional team work where and as required.

The introduction of the NDIS is leading to a disruption of the established systems and protocols in the different jurisdictions which provided for coordination and continuity of care and provision of high quality supports across all a person's environments and managed the issues that can arise where the mainstream services intersect and overlap. The breakdown of these arrangements creates increased risk as well as reduced participation.

Health system readiness

There is not currently capacity to offer the functional assessment and development of mealtime guidelines using health funding (as proposed by the NDIS).

As has been identified, these supports have previously been provided from the disability sector. A shift of the responsibility to provide these supports will require an expansion of the scope of practice for speech pathologists working in the health sector. Funding for provision of these supports has been shifted to the NDIS. A lack of funding for professional development within the health system will act as a barrier to any shift of these services to provision from the health sector.

The health sector would also need to develop and/or acquire the necessary resources e.g. accessible information sheets to support informed consent for assessment, visual supports for planning and decision making around mealtimes.

New health service delivery models would be needed to allow for:
- the same allied health professional/s who undertakes the functional assessment to also develop the mealtime guidelines AND provide the information and training to the paid and natural supports who are providing the direct support at mealtimes – which is critical to support best outcomes for the PWD
- dynamic assessment of functional oral eating and drinking skills in a person's everyday environments – including educational, care, recreational, home and accommodation settings.

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[2] RCSLT Dysphagia Manual: updated 18-06-2013-minor amendments 14/07/14
[3] RCSLT Dysphagia Manual: updated 18-06-2013-minor amendments 14/07/14

A full costing would be needed to identify the financial implications of the addition of these responsibilities as part of Health service delivery.

Within the current service delivery models, the person providing direct support will need to accompany the PWD to the tertiary health clinic venue in order to contribute to the assessment (which will entail either a personal cost, or a cost to the disability sector).

In meetings held in December representatives of the NDIS suggested that health funding for these supports could be via use of an MBS item. While this may be possible, the current Chronic Disease Management Plan would not provide for an adequate number (up to 5 allied health sessions per year) or length (20 minutes) of sessions. The CDMP also fails to provide for travel to see the participant in their home environment. PWD would be left with out of pocket expenses, which would act as another barrier to accessing these services, and as a consequence, to increased short, medium and long-term risks to health, Quality of Life and participation of PWD.

Risks with the shift of responsibility for funding to Health

As identified in the report of the Office of the Public Advocate in Qld[4] and the NSW Ombudsman[5] PWD who have oral eating and drinking difficulties who are living in residential accommodation services are at increased risk of avoidable death from choking, or respiratory illness associated with chronic aspiration.

The provision of a timely functional assessment and development of mealtime guidelines is a critical means to address this risk. The creation or exacerbation of barriers or delays to PWD being provided with comprehensive and high-quality supports for functional assessment and mealtime guidelines has the potential to increase the risk of death from choking and aspiration pneumonia in the short term, as well as creating increased risk of respiratory illness over the medium to long term. This will in turn lead to increased costs across both the Health and disability sectors.

There is a risk that barriers to provision of a dynamic assessment approach and/or the requirement for the PWD to attend a tertiary health setting which is unfamiliar and possibly distressing, will mean it is unlikely that an assessment of the person's oral eating and drinking skills would reveal their best ability. Services provided by clinicians working within a health system may be impacted by the risk averse medical model. These factors may in turn lead to the risk of more restrictive recommendations.

Imposition of more restrictive recommendation brings the risk of reduced engagement by PWD and their natural and paid supports, in functional assessment and access to recommendations for greater enjoyment, effectiveness and safety of mealtimes.

Delays in the ability to access supports from the health sector (because of waiting lists, or while capacity is being built) also creates the risk that PWD may be unable to access other disability or mainstream supports such as residential accommodation, recreational programmes, in home supports. Many organisations have had a policy, as part of their duty of care, of not providing direct support during mealtimes without a mealtime guideline provided by an allied health professional.

PWD whose oral eating and drinking difficulties don't result from a choking or aspiration risk will be unable to access the speech pathology supports they need to make their mealtimes enjoyable, effective and safe.

Recommendations

SPA believes that eating, drinking and swallowing are activities of daily living. Participation in enjoyable, effective and safe mealtimes improve functional and economic outcomes, social enjoyment and contribute to health and wellbeing.

Based on the information provided, SPA therefore recommends the following:

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[4] http://www.justice.qld.gov.au/__data/assets/pdf_file/0008/460088/final-systemic-advocacy-report-deaths-in-care-of-people-with-disability-in-Queensland-February-2016.pdf
[5] Report of Reviewable Deaths in 2012 and 2013 Volume 2: Deaths of people with disability in residential care

- Speech pathology support services and products which address functional impairments (which impact on participation in the activity of oral eating and drinking) and aim to improve functional capacity and provide support to live an ordinary life should be considered reasonable and necessary. Functional assessment of a person's eating and drinking, development of recommendations and development of mealtime guidelines should be funded in participant plans.
- SPA should be included (along with Dietitians Association of Australia and other relevant networks and alliances) to further refine the support role delineations for NDIA and mainstream health. The intersection with other sectors where direct support for mealtimes is provided should also be considered as part of this process.

Additional documents

Please see Appendix A for an analysis of the COAG principles deemed to be relevant to this decision.
If Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Catherine Olsson, National Advisor Disability, on 03 9642 4899 or by emailing disability@speechpathologyaustralia.org.au

Appendix A

COAG Principles to Determine the Responsibilities of the NDIS and other Service Systems, and provision of speech pathology supports for oral eating and drinking for people with disabilities

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COAG Principles

1. *People with disability have the same right of access to services as all Australians, consistent with the goals of the National Disability Strategy which aims to maximise the potential and participation of people with disability.*

   The Health system provides access to speech pathology supports for instrumental assessment, such as Video fluoroscopic Swallow Study(VFSS), Fibreoptic Endoscopic Examination of Swallow (FEES) and Modified Barium Swallow (MBS) for people with swallowing difficulties,

   Some people with disabilities experience barriers to their enjoyable, effective and safe participation in mealtimes. They require supports which are additional to and different from those required by people with dysphagia associated with an acute health condition (stroke, cancer, ABI etc).

   They may also require access to an instrumental assessment of dysphagia which is typically provided through the mainstream health system. While most instrumental assessments are provided to inpatients with acute health issues, the Health system also provides these services to outpatients, and should continue to provide them to people with disabilities and swallowing difficulties.

2. *The NDIS will fund personalised supports related to people's disability support needs, unless those supports are part of another service system's universal service obligation (for example, meeting the health, education, housing, or safety needs of all Australians) or covered by reasonable adjustment (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).*

   Speech pathology supports for oral eating and drinking aim to support enjoyable and effective, as well as safe, participation in mealtimes. Oral eating and drinking difficulties experienced by people with disabilities, including with swallowing, result from the body structure and function differences they experience because of their disabilities. While other populations may experience health risks arising from dysphagia, these are typically the result of an acute health incident (stroke, surgery for cancer etc), and largely short lived.

   In some cases, people may develop an acquired disability following an acute health incident and require ongoing speech pathology supports to facilitate their ability to have enjoyable, effective and safe mealtimes in their natural environments. Provision of these latter supports have not previously been part of any other service system's universal service obligation.

3. *Clear funding and delivery responsibilities should provide for the transparency and integrity of government appropriations consistent with their agreed policy goals.*

4. *There should be a nationally consistent approach to the supports funded by the NDIS and the basis on which the NDIS engages with other systems, noting that because there will be variation in non-NDIS supports funded within jurisdictions there will need to be flexibility and innovation in the way the NDIS funds and/or delivers these activities.*

   Given the risks and negative consequences which may arise out of any increase in the barriers to people with disabilities accessing timely and high-quality speech pathology supports for their oral

eating and drinking difficulties, provision of a consistent national approach offers increased likelihood of risk minimisation.

5. *In determining the approach to the supports funded by the NDIS and other service systems governments will have regard to efficiency, the existing statutory responsibilities and policy objectives of other service systems and operational implications.*

There are currently a number of barriers and challenges to using health funding to provide people with disabilities with collaborative, participation focussed, person-centred, and capacity building supports for oral eating and drinking.

The budgetary and policy implications for state/territory and the federal health systems could be considerable.

The delivery of this service by speech pathologists would not meet the current requirements for rebates under the MBS Chronic Disease Management (CDM) items for speech pathology services.
Additionally, the current CDM does not provide adequate sessions (up to 5 allied health sessions per year), or an adequate level of rebate (based on a 20-minute session provided in a clinical setting) to enable the provision of quality intervention.
This would create risks for people with disabilities and oral eating and drinking difficulties.
Australians with disability who have mealtime support needs will therefore need to privately fund these services or 'go without', impacting upon their ability to have, effective enjoyable and safe mealtimes.
This in turn creates a greater risk for developing medical complications (requiring hospitalisation and/or leading to premature death) or having to live with the risk of death from choking.
Shifting responsibility to fund speech pathology supports for oral eating and drinking to health will create a requirement for significant operational and policy changes in the health system.
Requiring people with disabilities to routinely and repeatedly engage with a health service delivery system which is disconnected from their ordinary life will lead to an increased burden for them as individuals, and on their supports, paid and informal.

Applied Principles: Health
Commonwealth and State and Territory health systems have a commitment to improve health outcomes for all Australians by providing access to quality health services based on their needs consistent with the requirements of the National Healthcare Agreement and other national agreements and in line with reasonable adjustment requirements (as required under the Commonwealth Disability Discrimination Act or similar legislation in jurisdictions).

SPA believes that funding through the health system for the provision of instrumental assessments of dysphagia (a quality health service is consistent with this principle.

2. The above health system will remain responsible for the diagnosis, early intervention and treatment of health conditions, including ongoing or chronic health conditions. This may involve general practitioner services, medical specialist services, dental care, nursing, allied health services, preventive health care, care in public and private hospitals, and pharmaceuticals (available through the PBS)

SPA would contend that the oral eating and drinking difficulties experienced by PWD, including dysphagia, is not a health condition per se (despite potentially contributing to premature/avoidable deaths for some people with disabilities), but is a functional (or activity) limitation (of the ability to eat and drink). While oral eating and drinking difficulties are associated with and impacted by a range of varied and interacting body structure and function impairments which arise out of people's developmental and acquired disabilities, there is also an interaction (in the case of supports with a functional aim) with contextual factors, in particular environmental factors. These environmental factors include environmental arrangement (e.g. considering where the PWD should be seated so that they are able to enjoy their meal without being distressed by the noise from others) and the knowledge, skill and attitudes of those providing (direct) mealtime supports.

SPA would contend that these issues are different from and additional to those issues which may be experienced at a broad population-based level, and do not fit with a definition of 'preventative health'. Additionally, while the supports provided may aim to reduce or eliminate the risk of choking and/or aspiration, and therefore have a focus on improved health outcomes, they also and inextricably focus on supporting the enjoyment and effectiveness of mealtimes – and therefore fit as much or more within the consideration for application of other principles.

Health systems are responsible for funding time limited, recovery-oriented services and therapies (rehabilitation) aimed primarily at restoring the person's health and improving the person's functioning after a recent medical or surgical treatment intervention. This includes where treatment and rehabilitation is required episodically.

This principle would indicate that the health system should be responsible to provide the time limited and recovery oriented speech pathology supports relevant to oral eating and drinking and dysphagia for PWD when and if these arise out of an acute health incident (e.g. CVA, ABI).such as those which may be experienced by other Australians.

The NDIS will be responsible for supports required due to the impact of a person's impairment/s on their functional capacity and their ability to undertake activities of daily living. This includes "maintenance" supports delivered or supervised by clinically trained or qualified health professionals (where the person has reached a point of stability in regard to functional capacity, prior to hospital discharge (or equivalent for other healthcare settings) and integrally linked to the care and support a person requires to live in the community and participate in education and employment

SPA would contend that the speech pathology supports aiming to support function (as provided through the disability sector prior to the transition to the NDIS) are consistent with supports as described in this principle.

If Speech Pathology Australia can assist in any other way or provide additional information please contact Ms Catherine Olsson, National Advisor Disability, on 03 9642 4899 or by emailing disability@speechpathologyaustralia.org.au

Speech
Pathology
Australia

Case Studies: NDIS position regarding funding of supports for Oral Eating and Drinking

This document has been prepared as a supplement to our briefing paper on the same topic. All scenarios have been reported by SPA members. They are drawn from several different states and territories and have been included because they are illustrative of impacts which will be felt if speech pathology supports for functional assessment of oral eating drinking, and development of guidelines for provision of direct supports, is not funded through NDIS Plans.

Please see the end of the document for a summary of issues.

Scenario 1

State: Victoria

The participant is a primary school aged student diagnosed with a syndrome which is degenerative and characterised by failure to gain weight and grow at the expected rate (failure to thrive); and deterioration of the nervous system. Additional signs and symptoms include weak muscle tone (hypotonia), sagging facial features, seizures, developmental delay, and intellectual disability. Oral eating and drinking guidelines are needed to ensure that those providing direct supports (at home, school and in the community) are supporting enjoyable, effective and safe mealtimes.

The family are accessing their first NDIS plan, which is currently being finalised. They have been informed by their planner (or Local Area Coordinator, or Early Intervention Partner) that they should not even apply for mealtime supports in their plan, as they are a "health issue".

No guidance was provided by the NDIS about where else they could go to access mealtime supports. The family's paediatrician referred them back into the RCH Eating, Drinking and Swallowing clinic. The child had previously been discharged from this service as it provides a swallowing assessment and consultation but not ongoing support for functional mealtime participation in the community.

The family feel frustrated and annoyed at being referred again to a service that they were aware they were no longer eligible for, and at the lack of support through the NDIS to access a community-based support for their child's oral eating and drinking needs.

The participant and their family both identified multiple impacts of mealtime issues on participation, mostly arising from prolonged mealtimes (reduced time to play and socialise at lunch and recess; reduced time for play, family engagement and homework at dinnertime; increased demands on family for support at mealtimes which in turn leads to a very different experience of mealtimes for the entire family etc.)

On presenting back to the RCH EDS clinic they were told that this clinic does not provide therapy. A letter was sent from the RCH to NDIS requesting that mealtimes be included in this child's plan given that the oral eating and drinking impacts are participatory, not health related (no risk of aspiration, as there are no pharyngeal stage issues, or malnutrition as the child has a Percutaneous Endoscopic Gastrostomy (i.e. formula is going directly into the stomach) in situ and they were subsequently discharged from the Health service once again.

The family are still seeking a means to access the speech pathology supports that they need.

Scenario 2

NSW

The participant is in their 20s with a progressive syndrome and presenting with late stage symptoms. It was identified that insufficient hours had been provided in the initial NDIS plan, and the NDIS assured the participant and providers that additional hours would be provided in the event of a decline.

The participant is now experiencing a decline in their condition. The supports provided have been exhausted managing the aspiration risk in the everyday environment. A review is currently being formally requested. As part of this process, the Planner provided the following feedback:

"The NDIS (Supports for participants) Rules 2013 state that Health systems are responsible for the diagnosis, early intervention and treatment of health conditions, including chronic health conditions. As the mealtime management plan is prepared by an allied health professional (Speech pathologist) to prevent a health condition such as aspiration pneumonia, the development of the plan is most appropriately supported by the health system.

Supports generally funded by the NDIS to manage dysphagia and mealtime support are:

- *A speech pathologist to educate and train informal (e.g. Carers/family) and other support staff on how to implement the mealtime plan recommendation for the Oral Eating and Drinking Care Plan (which is the South Australian and NSW terminology for a mealtimes guideline) ;*

- *Assistance such as a support worker to assist with the (sic) administering the mealtime plan, including managing behaviours of an NDIS participant of providing physical assistance to eat; and*

- *Review of assistive technology needs.*

Therefore, the assessment and management of the dysphagia including development of the OEDCP is not the responsibility of the NDIS.

The agency welcomes all feedback and I can coordinate this on your behalf if you would like.

Our member, who is the NDIS provider supporting this participant, then corresponded further with the NDIS to explain their concerns regarding the potential outcomes of no longer funding these supports through the individual's plan. (These are consistent with those which SPA has raised with the NDIA, and provided to the relevant Federal and State Ministers – see the SPA Briefing paper) .

A referral was made to Health, stating that a review was required within the following 2-3 weeks. The Health service referred the request back/onto the NDIS co-ordinator, as they were uncertain about the Health vs NDIS responsibilities, and of how the NDIS was likely to respond. The Health service in the client's area does not have an outpatient service (aside from oncology) and have stated that they are unable to provide home visits.

The participant consequently experienced a further decline in swallow function and demonstrated signs of aspiration, and the family was left in a position of having to transport the participant to hospital (20 mins away) and present to the Emergency Department for an assessment. The participant is unable to travel in a standard seat, so this will require transport in a wheelchair taxi. There is a risk of the participant demonstrating significant behaviours of concern in response to the taxi trip, and in the unfamiliar environment of the hospital, making it difficult to undertake a meaningful assessment of functional oral eating and drinking.

This participant is one of many being seen by this provider, where funds have either not been included in client plans (with the same reasons stated as per above) or, where they have been available under a line

item which could be used by the provider to claim, local planners have told families they are unable to use these funds for supports for functional oral eating and drinking.

Scenario 3

South Australia

The participant is a young teenager with cerebral palsy leading to significant physical disability. The child uses an electronic aided communication device (which there is also a delay with provision of via the NDIS) and has recently commenced first year at a mainstream high school.

Most nutrition is provided using a PEG (i.e. feeds going directly to the stomach) because of the time and effort to take food orally, and difficulties with the process of swallowing. The child has previously had a mealtime guideline provided to allow the support worker at school to offer 'tastes' of food – for pleasure, to help develop/maintain oral motor and sensory function, and to be able to be part of the 'gang' of peers, who are eating orally during shared mealtimes. The family and speech pathologist had recommended that this be supported at school during the day, as by the time of the evening meal, the level of fatigue for the child is impacting on swallowing function. The child's parents hadn't realised until recently that the school was no longer providing supports as a result of the mealtime guideline which had been in place being out of date.

The family requested funding for a speech pathologist to provide a functional assessment of oral *eating and drinking and to develop a guideline. The NDIS Planner provided the following response.*

"Regarding the request for Xi's Oral Eating and Drinking Care Plan (OEDCP): given that the primary purpose of OEDCPs is to manage and reduce the clinical risk of choking or aspiration during a mealtime and thus prevent the development of a medical condition such as pneumonia. As per COAG principles and NDIS rules; preventative health care is the responsibility of the Health system, and as OECDPs are a preventative treatment plan to avoid the development of a health condition, they are not able to be funded under an NDIS plan."

The family then escalated the issue to the local NDIS Manager

"NDIA rejected X's application for OEDCP (Oral Eating and Drinking Care Plan) and sent us to health . When I spent a day away from my work to phone and write to Health managers – …….. (they) have made clear statements that this is an NDIS responsibility. X 's oral functioning has regressed considerably due to not having food in the mouth – this is not just an important health issue but also a social issue – how many of us would enjoy sitting with other school kids and watch THEM get to eat or to go out to dinner to WATCH EVERYONE ELSE EAT?"

The NDIS Manager followed up at higher levels with both Health (i.e. State paediatric health service) and within the NDIA – with the outcome of the participant's parents being informed that they would need to request that their GP provide a Chronic Disease Management Plan (CDMP).

As discussed in the briefing paper prepared by SPA, not only does a CDMP offer an inadequate number of sessions annually (maximum of five) and an inadequate rebate (maximum of $55.57, based on an assumption of a 20-minute session), it doesn't provide for the cost of travel (to undertake an assessment of function in a meaningful context). This 'solution' proposed by the NDIS also creates inefficiencies in service delivery, the costs of which are effectively transferred to the Federal Government via Health and or the individual participants and creates additional barriers and burdens for people with disability (PWD) and their natural supports, in accessing the 'reasonable and necessary' supports to enable participation in an everyday life activity.

Scenario 4

Qld

The participant is 39 years of age and has complex communication needs and a significant intellectual disability associated with Down Syndrome and lives in supported accommodation. A speech pathologist was engaged to contribute to providing solutions for some behaviours of concern. The person had ongoing oral eating and drinking issues.

Workers in the house were using guidelines which has been provided in 2013. Though these recommended minced and moist food texture, staff in the house were blending to a pureed texture due to a belief that this would be 'safer' i.e. they were applying a more conservative/restrictive approach and therefore impacting on this person's choices and quality of life.

In this instance the speech pathologist was approved to provide a functional assessment of oral eating and drinking, and new guidelines, using NDIS funding – but this scenario illustrates that oral eating and drinking supports provided by speech pathologists are not always or exclusively about preventing aspiration or choking and therefore not a "preventative health" issue.

It is also an illustration of the risks, should PWD be required to attend a health service for an assessment of their functional oral eating and drinking. In the case of this participant, it is very likely that if an assessment of swallowing was undertaken in an unfamiliar hospital setting the person would be unlikely to demonstrate their optimal ability, in turn leading to continued provision of more conservative and restrictive recommendations.

Scenario 5

NSW

A physiotherapist colleague reported of two participants living in a group home with significant needs in relation to oral eating and drinking. When their NDIS plans were reviewed, the Planner removed funding for speech pathology, dietetics and some of their Occupational Therapy, stating that it is "the responsibility of Health to provide these supports".

It is unclear what the further outcomes for these participants were as we have not had further contact (at SPA) from the provider involved – but this scenario does demonstrate that the NDIS (and/or Planners) are acting based on the NDIS 'position' regarding provision of speech pathology supports for oral eating and drinking, in the absence of an agreement at the COAG level, and with no arrangements in place to offer an alternative means to access these supports, leading to significant concerns and frustration for participants and allied health providers alike.

Scenario 6

NSW

This child is aged 7 years with chromosome deletion, with delayed oral eating and drinking skills, as well as delayed gross motor, speech and language and cognitive development. The child had previously had supports for oral eating and drinking through Ageing, Disability and Home Care (ADHC) and a tertiary paediatric health service. There were a range of functional limitations and impact on participation, but the swallow was safe and no signs of aspiration.

Speech pathology services were provided monthly, in both the home and school context, and using a collaborative team approach involving the Occupational Therapist, and the teacher's aide who supported the child at mealtimes. The child was provided with a total of 17 sessions over 2 years, and achieved

significant gains, including moving to drinking using a cup instead of a bottle, using a straw to drink, starting to chew foods (rather than using an immature and inadequate 'sucking' pattern), beginning to eat soft chewables (rather than just mashed foods), beginning to manage finger foods (and therefore eat independently) at school.

During the planning process for the child's third plan, NDIS funding for oral eating and drinking was denied because the intervention was determined by the Planner to be for "weight and nutritional reasons". The Planner suggested the family see a Dietitian. The child has no nutritional or weight issues – the focus of therapy is around continuing to support the family to provide appropriate 'challenges' for the child, to provide opportunities for the development of improved skills for eating and drinking, and to support the ability of those providing direct supports for mealtimes, for these to be effective, enjoyable, and safe.

Summary of issues:

- Speech pathology supports for enjoyable, effective and safe mealtimes for PWD have previously been provided through disability services.

- Speech pathologists provide these supports with a broad focus, including: developmental (for children's eating and drinking skills), participatory (including the social, emotional and community participation-based aspects of mealtimes), nutritionally effective (e.g. balancing the time and effort involved in taking food orally, with their nutritional and hydration needs) and safe (reducing or eliminating the risk of choking or aspiration).

- The NDIS believes that these supports for functional oral eating and drinking are either solely or primarily addressing health risks and are therefore 'preventative health' and should be funded through the health system. The NDIS is apparently operationalising this 'position' as part of the development of individual plans, despite no decision having been reached by the Disability Reform Council. This creates significant risks both to PWD's participation and health.

- Health services do not currently have the capacity, expertise or infrastructure to provide functional mealtime supports to PWD in the optimal environment, i.e. their home, school or other community setting. These services were previously provided by Disability services.

- Health continues to provide instrumental assessments of swallowing (for people with oropharyngeal dysphagia) and assessment and intervention for people who have had acute health incidents (e.g. stroke, brain injury, surgery) which impact on swallowing function.

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[i] Information has been de-identified

Speech Pathology Australia Member Feedback Case Study - auditing costs

Quotes obtained for 3 year certification of a medium sized private practice in Sydney.

The practice has 19 professionals (across Occupational Therapy, Speech Pathology and Physiotherapy) and service approximately 400 NDIS clients across the lifespan from early childhood to adults and are registered for 13 different registration groups (both low and high risk).

They were previously audited in 2016 against the NSW Disability Service Standards at a cost of only $5000.

Company	Audit Price / Comments
BSI Group (Australia and New Zealand) Pty Ltd	$18,213.80
DNV GL Business Assurance Australia Pty Ltd	$11,404.25
Global-Mark Pty Ltd	$30,129
HDAA Australia Pty Ltd	**Unable to provide quote due to high demand**
Institute for Healthy Communities Australia Certification Pty Ltd	**Unable to provide quote due to high demand**
Q-Audit Limited	**Unable to provide detailed quote due to high demand**
Quantum Certification Services Pty Ltd	$30,360
SAI Global Certification Services Pty Ltd	**$35,585 reduced to $19,541**

NATIONAL GUIDELINES

BEST PRACTICE IN EARLY CHILDHOOD INTERVENTION

CONTENTS

1 : BACKGROUND

WHAT IS EARLY CHILDHOOD INTERVENTION?

Early Childhood Intervention (ECI) is the process of providing specialised support and services for infants and young children with disability and/or developmental delay, and their families, in order to promote development, well-being and community participation www.ecia.org.au

Tim Moore, leading expert in ECI, states that the overall aim of ECI is to ensure that the parents or other key caregivers are able to provide young children who have disability and/or developmental delay with experiences and opportunities that promote the children's acquisition and use of competencies which enable the children to participate meaningfully in the key environments in their lives (2012).

ECI practitioners work in partnership with parents/caregivers, families and other significant stakeholders to enhance their knowledge, skills and supports to meet the needs of the child, optimise the child's learning and development, and the child's ability to participate in family and community life (Bruder, 2010; Dunst, 2007).

WHY ARE THE EARLY YEARS IMPORTANT?

The early childhood years lay the foundation for all future development. Recent scientific evidence shows that early experiences shape our lives by affecting the way the young brain develops. What happens to us in the early years has a major effect on our health and social development through to adulthood. Therefore, we must ensure that children's early experiences are positive - that they have a secure foundation for development. (Sameroff, 2009; Shonkoff, 2010; Shonkoff & Phillips, 2000; Sroufe, 2009; Worthman et al., 2010).

The early childhood years are just as important for children with disability and/or developmental delay as they are for all children. All their future development is based on the critical learning patterns laid down during this period.

The early years are also critical for the whole family. This is when families can best begin to learn how to support and nurture their child, how to meet their child's needs, and how to adapt positively to having a child with disability and/or developmental delay.

The earlier a child is identified as having disability and/or developmental delay, the more likely they are to benefit from strategies targeted towards their needs. The success of early intervention strategies not only assists families through the provision of extra support for their child, but also decreases costs to schools and communities in the later years as children transition to school (Bruder, 2010).

THE EARLY INTERVENTION SEVEN KEY PRINCIPLES: LOOKS LIKE/ DOESN'T LOOK LIKE

The Early Intervention Seven Key Principles: Looks Like/ Doesn't Look Like presents in plain language best practice principles and their application for infants and toddlers in ECI settings. The seven universal principles identified are:

1

Infants and toddlers learn best through every day experiences and interactions with familiar people in familiar contexts.

2

All families, with the necessary supports and resources, can enhance their children's learning and development.

3

The primary role of the service provider in early intervention is to work with and support the family members and caregivers in a child's life.

4

The early intervention process, from initial contacts through to transition, must be dynamic and individualised to reflect the child's and family members' preferences, learning styles and cultural beliefs.

5

Individual Family Service Plan outcomes must be functional and based on children's and families' needs and priorities

6

The family's priorities, needs and interests are addressed most appropriately by a primary provider who represents and receives team and community support.

7

Interventions with young children and family members must be based on explicit principles, validated practices, best available research and relevant laws and regulations. (WPPNE, 2008)

This document is endorsed by the NDIA and can be accessed on the NDIA website.

EARLY CHILDHOOD INTERVENTION AUSTRALIA (ECIA)

Early Childhood Intervention Australia is the peak body for early childhood intervention in Australia, representing professionals and organisations that provide services for young children with disability and/or developmental delay and their families.

EARLY CHILDHOOD INTERVENTION UNDER THE NATIONAL DISABILITY INSURANCE SCHEME

ECI services in Australia will henceforth be delivered via the National Disability Insurance Scheme (NDIS) under the auspices of the National Disability Insurance Agency (NDIA) the independent statutory agency whose role is to implement the NDIS or possibly the Disability Service Commission (WA only) depending on the outcome of an independent evaluation.

The NDIS is new to disability service provision in Australia and provides a set of agreements that ensures that there is a single consistent scheme for the provision of disability support services across all Australian states and territories. It provides funding directly to individuals who are able to choose their own services and purchase directly from providers. The NDIS will essentially mean the end to 'block funding' from government to service providers. It is expected that the scheme will be fully operational in most jurisdictions and the sector transition complete by the year 2019-20.

The NDIS enables participants to access reasonable and necessary supports, including early intervention, with more choice and control over how, when and where supports are provided.

ECIA considers early childhood intervention as supporting a child's development of functional skills that would enable them to participate meaningfully in everyday activities alongside typically developing peers. Early childhood intervention supports need to be provided in a way which is inclusive of the family so that activities are targeted to encourage the learning and development of the child and are reinforced and complemented in family settings. In this sense, the goals of the family, their values and priorities need to be integral to the developing early intervention approach to ensure that ECI will make the most significant impact (ECIA, NSW Chapter, 2014).

RATIONALE FOR NATIONAL GUIDELINES ON BEST PRACTICE IN EARLY CHILDHOOD INTERVENTION

Current practices in ECI in Australia vary across and within states and territories. As a national scheme, the NDIS requires national guidelines on best practice that may be consistently applied in all states and territories.

The purpose of these guidelines and recommendations is to provide a framework for universal and equitable high quality ECI based on best practice for children with disability and/or developmental delay whether they attend government, non-government, large, small, sole non-for-profit service providers or private providers, anywhere in Australia.

DEVELOPMENT PHASE OF THE NATIONAL GUIDELINES ON BEST PRACTICE

These guidelines and recommendations draw upon extensive consultation with the ECI sector and key stakeholders.

In May and June 2015, ECIA undertook a series of consultation workshops across Australia. The starting point for discussions with the ECI sector on the best practices in ECI was the Early Intervention Best Practice Discussion Paper developed by ECIA in 2014. This paper was distributed as pre-reading for the National Guidelines consultation workshops.

The objectives of these workshops were to:

- review current practice in Early Childhood Intervention across Australia;
- identify key best practices in ECI that are agreed upon by the ECI sector and its stakeholders across Australia;
- identify any environmental factors impacting upon current ECI practice;
- identify strategies to address gaps between current ECI practices and best practice in ECI

Over 400 participants attended these workshops in eleven diverse locations across Australia. Locations included Geelong, Melbourne, Sydney, Newcastle, Canberra, Brisbane, Rockhampton, Darwin, Perth, Adelaide and Hobart. Eleven submissions from key organisations on the Guidelines on Best Practice were also received. The workshop reports make for a unique insight into the state of practice in early childhood intervention across the country. Please go to the ECIA National website to view the Emerging Themes Reports for each of these workshops.

The feedback provided to ECIA during the consultation phase of the National Guidelines project was then cross-referenced against Australian and international research and literature in Early Childhood Intervention.

The final consultation was engagement with the Expert Advisory Group (EAG) which consists of 60 experts in a diversity of fields related to ECI. They were asked to critically review the final draft document.
For a full list of the EAG members go to: www.ecia.org.au/advocacy/eci-national-guidelines-project

From the review of current literature and extensive consultation with the ECI sector, four quality areas were identified comprising of eight key recommended best practices in ECI which are found on the following page. The rationale for each of these best practices can be found in Section 3: Rationale for Key Best Practices in ECI (p.9).

2 : KEY BEST PRACTICES IN EARLY CHILDHOOD INTERVENTION

From a review of current international and Australian literature and extensive consultation with the ECI sector, four quality areas were identified comprising of eight key best practices in Early Childhood Intervention (ECI).

QUALITY AREA 1: FAMILY

1. **Family-Centred and Strengths-Based Practice:** is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

2. **Culturally Responsive Practice:** creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

QUALITY AREA 2: INCLUSION

3. **Inclusive and Participatory Practice:** recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

4. **Engaging the Child in Natural Environments:** promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

QUALITY AREA 3: TEAMWORK

5. **Collaborative Teamwork Practice:** is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

6. **Capacity-Building Practice:** encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development.

QUALITY AREA 4: UNIVERSAL PRINCIPLES

7. **Evidence Base, Standards, Accountability and Practice:** ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high quality services.

8. **Outcome Based Approach:** focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

3 : RATIONALE FOR KEY BEST PRACTICES
IN EARLY CHILDHOOD INTERVENTION

From a review of current international and Australian literature and extensive consultation with the ECI sector, four quality areas were identified comprising of eight key best practices in Early Childhood Intervention (ECI). The rationale for each of these best practices is detailed below.

QUALITY AREA 1: FAMILY

1. Family-Centred and Strengths-Based Practice: is a set of values, skills, behaviours and knowledge that recognises the central role of families in children's lives. Family-centred practice is a way of thinking and acting that ensures that professionals and families work in partnership and that family life, and family priorities and choices, drive what happens in planning and intervention. Family-centred practice builds on family strengths and assists families to develop their own networks of resources – both informal and formal.

Within Australian and international ECI literature, family-centred and strengths-based practice are considered best practices (Dew et al. 2014; Fordham et al. 2012). There was broad consensus across the ECI National Guidelines consultation workshops on these practices and that family-centred practice, in particular, is the foundation for best practice in Early Childhood Intervention.

FAMILY-CENTRED PRACTICE

Family centred practice is made up of a set of values, attitudes and approaches for working in partnership with children and their families. Family centred practice is not just a specialist way of working with a child with disability and/or developmental delay, and their families, but is now established best practice for anyone working with children and families. In fact, it has rapidly emerged as the preferred model for working with people of all ages and circumstances.

There is now strong evidence for the approach, including that it improves child behaviour and wellbeing, family functioning, levels of social support available to families and family satisfaction with services, and that it contributes to these primarily by increasing parental self-efficacy (Dempsey & Dunst, 2004; Dempsey & Keen, 2008; Gavidia-Payne et al., 2015; Guralnick, 2011). Importantly, family-centred practice, is indirectly linked to improved developmental outcomes for the child, through building the self-efficacy of the family (Dunst & Trivette, 2009). The approach is also supported in school settings by evidence of the benefits of family–school partnerships for all students (DHS & DEECD, 2012).

FAMILY CENTRED PRACTICE RECOGNISES THAT:

- Each family is unique and different.
- The family is the constant in the child's life.
- The family is the expert on the child's abilities and needs.
- Optimal child functioning occurs within a supportive family and community context; the child is affected by the stress and coping of other family members.

GUIDING PRINCIPLES OF FAMILY CENTRED PRACTICE:

- Each family should have the opportunity to decide the level of involvement they wish in the decision making for their child.
- Parents have ultimate responsibility for their child.
- Each family and family member should be treated with respect.
- The strengths and needs of all family members should be supported and encouraged.

(Law et al., 2003; CCCH, 2004. DHS & DEECD, 2012).

As children learn in the context of their families, families are the primary influence on children's learning and

development (Bruder, 2010; DEECD, 2011). A key role of ECI is to support parents/caregivers and educators to enable them to provide children with experiences and opportunities that promote using and developing their skills (Moore, 2012). Families, educators and community partners who feel respected and supported by ECI practitioners and who feel competent in the skills needed to interact with the child are better able to promote a child's social, cognitive and behavioural developments (Gavidia-Payne et al., 2015).

A model developed by Dunst, Trivette and Deal (1988) on enabling and empowering families has influenced the thinking about family centred practice for decades. The model has since been expanded to a Helpgiving Practices model (Dunst 2010; Dunst & Trivette, 2009; Dunst et al., 2007) which identifies three key components of effective capacity-building family-centred helpgiving:

- Relational practices build relationships and are about the help giver's beliefs, values and attitudes, and their interpersonal behaviours and skills.

- Participatory practices are where the help giver empowers families to make informed decisions and take action, and ensures that the help giver responds to each family's unique and changing needs.

- Technical quality is about the help giver having the information, knowledge and expertise needed to deliver high-quality supports and services, and applying it for the benefit of children and families.

Research and clinical practice have increasingly indicated that how help is provided is as important as what is provided if help giving is to have positive consequences (Dunst & Trivette, 2009; Dunst et al., 2007). The ability of ECI professionals to support families depends not only on their technical knowledge and skills in working with children with disability and/or developmental delay, but also upon their personal qualities and skills in building positive working relationships with parents and supporting family's choice and participation (Moore, 2012).

Providing family-centred services can be a challenge to some practitioners. Family-centred practice does require a shift in power and authority away from the professional as 'expert' and key decision-maker and towards the family. In fact, additional expertise is required to empower families (DHS & DEECD, 2012).

Partnering with families and communities to support a child to learn, grow and thrive is an integral part of family-centred practice. ECI professionals share their professional expertise and knowledge with the family and at the same time regard the family's expertise as valid, significant and valuable. They position themselves as knowledgeable consultants who support families' choices and values. Providing families and their social supports with information can, in itself, enable families and other key stakeholders to make choices and decisions (Bailey & Powell, 2005; Fordham et al., 2012).

STRENGTHS-BASED PRACTICE

All families, with the necessary supports and resources, can enhance their children's learning and development (WPPNE, 2008).

Strengths-based practice builds on family members' competencies; supports families to make decisions for themselves; and focuses on empowering families to do things for themselves within their social communities. Rather than focusing on correcting peoples' weaknesses or problems, capacity-building and strength-based strategies recognise the assets and talents of people and help people use these competencies to strengthen functioning (Caspe & Lopez, 2006; Dunst & Trivette, 2009; Dunst, 2007).

For the child, strengths-based practice means that ECI practitioners focus on what each child can do, or shows emerging ability to do in different contexts, and on the opportunities these afford, rather than what the child is not able to do and potential barriers to development (ECIA, NSW Chapter, 2014).

Effective ECI services build on the existing strengths of children, families and the communities in which they interact. Focusing on existing strengths promotes an individual's sense of control and is integral to facilitating empowerment (Dempsey & Dunst, 2004). ECI services that adopt a strengths-based practice are more effective and empowering to families and community stakeholders leading to better long-term outcomes (Green et al., 2004).

For the ECI practitioner, it also requires an awareness and understanding that all families are resourceful but do not always have the ability or knowledge to access the resources and supports they require.

Increasingly, ECI practitioners are faced with families with complex and multiple needs. All families, including

families of children with disability and/or developmental delay, face a range of factors that can compromise parental, personal and family functioning. These include factors such as housing, finances, transport, social support, parental/caregiver physical and mental health, drug and alcohol issues and family violence (Moore, 2012). The presence of one or more of these factors can undermine parents' and caregivers' abilities to address their children's needs, and is particularly so for families with complex cultural backgrounds such as Aboriginal and Torres Strait Islander and migrant families (Guralnick, 2011).

It is imperative that these risk factors and needs are addressed in a holistic manner in order to affect any meaningful and sustainable change, improve family functioning and ensure the child has the required supports. If these factors are not addressed, they will undermine the family's capacity to put supports around their child and jeopardise achievement of positive outcomes.

The essential task for ECI practitioners in delivering family-centred and strengths-based programs is to identify the strategies and experiences that will suit the needs and circumstances of a particular family, and to work with the family to build these strategies into their everyday life (Dunst & Trivette, 2009; KPMG, 2014; Guralnick, 2011; CCCH, 2011; Moore, 2012). The ECI practitioner must have a good knowledge of the community system so that they can link families into appropriate universal services and then to provide assistance to support these services to accommodate the needs of the family and child if necessary. An important point for practitioners to remember is that families do have the right to make choices for themselves and their child unless they contravene the law.

2. Culturally Responsive Practice: creates welcoming and culturally inclusive environments where all families are encouraged to participate in and contribute to children's learning and development. Practitioners are knowledgeable and respectful of diversity and provide services and supports in flexible ways that are responsive to each family's cultural, ethnic, racial, language and socioeconomic characteristics.

> *In all of the consultation workshops, culturally responsive practices or cultural competencies were highlighted as an important best practice. It was acknowledged that ECI practitioners need to be more culturally responsive and culturally competent to work effectively with the diversity of families across Australia. Respecting diversity of families was noted as a key feature central to family-centred practice.*

Culturally responsive practice and family-centred practice are deeply linked because culture profoundly shapes both human development and family structures, whatever a family's culture. Children's personal, family and cultural histories shape their learning and development (DEECD, 2011). A family's culture may also affect attitudes, values, beliefs and capacities across a number of areas including: child-rearing practices; health practices; meanings of disability; perceptions of education; and perceptions of ECI (Madden, 2005).

Family-centred practice requires services to take into account each family's socio-cultural and socio-economic related expectations for development and participation (Dew et al., 2014). Families are less likely to participate or stay engaged with ECI services when their cultural background is ignored (CCCH, 2011).

Culturally responsive practice is when professionals and organisations respond respectfully and skilfully to the needs of diverse communities. It can be seen as part of a broader concept of cultural competence, described as a set of 'congruent behaviours, attitudes and policies that come together in a system or agency or among professionals' that enable effective work in cross-cultural situations (National Medical and Health Research Council in DHS & DEECD, 2012). A lack of adequate cultural competencies, including personal maturity and thoughtfulness in outlook and practice, ability to achieve functional therapeutic outcomes with interpreters, ability to work with community leaders/educators and use translated resources effectively is a significant barrier to working with culturally and linguistically diverse families and Aboriginal and Torres Strait Islander families (Dew et al., 2014; Lindsay et al., 2012).

Translation and interpretation services for families where English is not their first language is an important part of being culturally competent. Where possible an appropriately skilled interpreter should be offered to avoid difficulties that might arise from having family members or friends interpret.

However, family preferences must be considered and there may be occasions where it is most appropriate for a family member or friend to interpret. Other needs and priorities of the family should be respected in the selection of the interpreter - factors such as the interpreter's gender and religion may also be important

(Madden, 2005).

Recognising the complexities contributing to a family's diversity, respecting the family's personal and social resources and being able to cater to diversity are key features of family-centred practice (Dew et al., 2014). Understanding the practices, values, beliefs and cultures of families, and the immediate and extended communities in which they interact are fundamental to the best practice of ECI.

QUALITY AREA 2: INCLUSION

3. Inclusive and Participatory Practice: recognises that every child regardless of their needs has the right to participate fully in their family and community life and to have the same choices, opportunities and experiences as other children. All children need to feel accepted and to have a real sense of belonging. Children with disability and/or developmental delay may require additional support to enable them to participate meaningfully in their families, community and early childhood settings.

> *There was broad consensus across all ECI National Guidelines consultation workshops on the importance of inclusion. The Early Childhood Intervention Australia (ECIA) and Early Childhood Australia (ECA) 2012 statement, 'Position on the Inclusion of Children with Disability in Early Childhood Education and Care', has contributed to raising people's awareness of the rights of children with disability and/or developmental delay to be included not only in Early Childhood Education and Care settings (ECEC) but in all aspects of community life. However, there is still work to be done to enable children to participate meaningfully in inclusive settings and have a 'sense of belonging.'*

Inclusion is the active participation of children with and without additional needs, within their family, early childhood programs and community settings. Children spend the majority of their time with their families in everyday routines and activities (Bruder, 2001; Jung, 2003). Their main learning environment is the family, with community settings and early childhood programs playing an increasingly important role as they grow older. Inclusion is not just about children with disability and/or developmental delay attending mainstream programs, but about creating environments for all children to be able to develop relationships, have opportunities enabling meaningful engagement and participation in all activities (DEECD, 2011; ECIA, NSW Chapter, 2014;). Participation is more than being present in different environments –it means being actively engaged. For participation to be meaningful, the person's role and contribution must be valued by all those involved in the activity, including the person themselves (Moore, 2012).

Children with disability and/or development delay benefit from interacting and participating in activities and settings with children without disability (Bruder, 2010; Case-Smith & Holland, 2009; CCCH, 2011). Research has demonstrated that children with disability are more interactive in inclusive settings than in segregated settings providing greater opportunities for children to develop friendships (Antia et al., 2011; Case-Smith & Holland, 2009). Children without disability also experience positive outcomes in inclusive settings (CCCH, 2011).

Successful inclusion of a child depends upon the attitudes and beliefs of all concerned: parents, ECEC staff, children, and community members. In fact, attitudes, assumptions and beliefs of community members are perceived by individuals with disabilities to be the single greatest barrier to their achievement of life goals (King et al., 2002). However, a wide variety of other factors also influence the way in which inclusion is implemented and viewed by families and practitioners such as child and adult characteristics, and policies and resources (King, 2006). A collaborative project by ECIA and ECA to develop a joint position statement on the inclusion of children with disability in ECEC settings found that the beliefs, attitudes and values of early childhood practitioners were seen as key to successful inclusion of children with disability and/or developmental delay. Staff were more likely to remain negative about inclusion if they felt inadequately trained and supported to provide inclusive programs. Training and support for staff to work effectively with children with disability was linked to improved attitudes by respondents (Forster et al., 2013).

The NSW's Strengthening Supports for Children and Families 0-8 Years: Now and Into The Future (FACS, 2015) reflects on the first three years of the strategy saying that:

> *'there has been a strong focus on changing culture and practice within the disability sector. We need to*

continue to build a culture where mainstream community settings, including family support, early childhood education and care, Family and Community Services, education and health settings, are the natural context for young children and their families, with early intervention supports merged within these settings to develop inclusive communities. We will know we have made progress when families and mainstream settings work in partnership to co-produce outcomes aimed at improving a child's life in the context of their family and meaningful participation in their community.'

For inclusion to be successful, families, early childhood service providers and community service providers must be provided with specialist support to meet their needs, and to enable them to help children develop the skills to participate meaningfully in everyday activities. There is clear evidence that, without purposeful adaptations and strategies, children with disability are not involved in as many activities as other children (Odom et al., 2011; National Professional Development Center on Inclusion, 2011; CCCH, 2014). Ensuring participation involves using a range of intervention approaches to promote engagement and a sense of belonging for each child (Buysse, 2012).

Assisting caregivers to develop positive and responsive relationships with their child with disability and/or developmental delay from as early an age as possible should be a major focus of early childhood intervention services. Support can include direct support from ECI practitioners, ongoing professional development, collaboration and co-ordination among key stakeholders, public policies and resources, and research and evaluation (Buysse, 2012). For inclusion to be effective, service providers must ensure that all aspects of program design, including policies, laws, institutions, services, facilities and technologies are developed on principles of universal design (Darragh, 2007). All programs need to build their capacity to cater for all children, and provide supports across the complete spectrum of abilities, cultures, and circumstances (ECIA, NSW Chapter, 2014).

4. Engaging the Child in Natural Environments: promotes children's inclusion through participation in daily routines, at home, in the community, and in early childhood settings. These natural learning environments contain many opportunities for all children to engage, participate, learn and practise skills, thus strengthening their sense of belonging.

There was broad consensus across all ECI National Guidelines consultation workshops on engaging the child in natural environments- however, respondents strongly recommended that the terms 'natural learning environment' and 'working with a child through daily routines' be clarified for use by the Early Childhood and Early Childhood Intervention sectors.

Natural environments are settings, where children learn and develop everyday abilities and skills, including the home, community, and early childhood centres (Dunst & Bruder, 2006). Natural environments are full of opportunities for children to practise, master and expand their skills and learning (Sandall & Schwartz, 2008). Learning skills in a natural environment is more effective than practising a new skill in an isolated setting once or twice a week (Case-Smith & Holland, 2009; Dunst et al., 2010b).

Delivering interventions in natural environments involves the people who are part of the children's lives (FACS, 2015). Children's ongoing learning depends upon having repeated opportunities to practise developmentally appropriate skills in everyday situations with support from caregivers and community members (WPPNE, 2008).

The way in which parents and caregivers engage children is critical for their overall development (Dunst, 2006; Dunst & Swanson, 2006; Karaasian & Mahoney, 2015). Promoting responsive caregiving is therefore an essential first step in ensuring that children build secure relationships with caregivers and early childhood service providers. Engaging children by capturing their interests creates opportunities to sustain learning, supports current competencies and facilitates development of new competencies (CCCH, 2014; Davis, 2014; Dunst & Bruder, 2006). Children are active participants in their own development and active involvement builds understanding of concepts, creative thinking and the inquiry processes necessary for lifelong learning (McWilliam, 2010a; DEECD, 2011).

Interventions are more effective when they reflect everyday activities and routines such as getting dressed and mealtimes (Bruder, 2010; Dunst et al., 2010; McWilliam, 2010a). The sequence of routines and their repeated nature provide opportunities for children to acquire and refine skills (Hughes-Scholes et al., 2015). In the context of everyday routines, a good facilitator can incorporate additional learning opportunities reflecting individual goals and interests (Campbell et al.; 2009).

Parents prefer interventions that are meaningful, easy to do, fit into their daily lives, and support their child in learning skills that help them be part of family and community life (Dunst et al 2010). When parents provide intervention in daily routines they are more likely to attribute progress to what they do between home visits, rather than to what the professional does during a home visit (McWilliam, 2010a; McWilliam, 2010b).

QUALITY AREA 3: TEAMWORK

5. Collaborative Teamwork Practice: is where the family and professionals work together as a collaborative and integrated team around the child, communicating and sharing information, knowledge and skills, with one team member nominated as a key worker and main person working with the family.

There was broad consensus across all ECI National Guidelines consultation workshops that collaborative and coordinated teamwork was an essential best practice for ECI. Currently under the NDIS, best practice teamwork in ECI is defined as 'transdisciplinary family centred key worker' or a 'transdisciplinary service model early childhood intervention.' However, because the word 'transdisciplinary' has now become more closely associated with a 'funding line' than a model of team interaction teamwork, we now understand the need to define collaborative teamwork practice and related terminology so there is consistency across Australia. This work has been initiated in a research paper developed for the NDIS by Moore (2013) 'Team work in early childhood intervention services: recommended practices.'

Below we describe how current teamwork models have developed over time and then define concepts essential to collaborative teamwork with 'collaborative teamwork' the preferred teamwork model that best reflects contemporary practice. It is a flexible, easily understandable model of teamwork interaction that will best meet the needs of families and, not only the ECI sector, but major partners in the ECEC sector, education, health and family support areas as they increasingly engage with providing supports to children and their families under the NDIS.

TEAMWORK MODELS OF INTERACTION

Providing families with choice and control is central to the NDIS. This extends to providing families with a choice of provider, including the potential for families to bring together a team of providers who can deliver the range of required supports in the ways, places and at the times that best match their family's needs. Children with disability and/or developmental delay may require the combined expertise of a range of practitioners and specialised services including medical personnel, therapeutic practitioners and educational and developmental experts. There are a range of approaches to 'teamwork' including multidisciplinary, interdisciplinary, transdisciplinary and, more recently, the key worker and Team Around the Child (TAC) models with 'collaborative teamwork' combining some of the key elements of the transdisciplinary, the key worker and the TAC teamwork models.

MULTIDISCIPLINARY TEAMWORK

In multidisciplinary teams, a range of professionals work independently with the child and have limited interaction with one another (Briggs, 1997). Specialists conduct their own assessments, develop their own set of goals and provide interventions directly with the child. The advantage of this model is that it maximises the specialist skills of the different professionals. However, the lack of co-ordination means there is a high risk of professionals providing contradictory advice and of making cumulative demands upon families that are unrealistic and highly stressful (Moore, 2013). Lack of communication between team members also places the burden of coordination and case management on the family.

INTERDISCIPLINARY TEAMS

Interdisciplinary teams comprise parents and professionals from several disciplines who have formal channels of communication (Briggs, 1997). Representatives of various professional disciplines assess children and families separately, but the team meets to discuss the results of assessments and develop plans for intervention. Generally, each specialist is responsible for the part of the service plan related to his or her professional discipline. Although this approach solves some of the problems associated with multidisciplinary teams, families are not consistently recognised as equal team members and coordination of services continues to be a problem. There is evidence that families find the constant rotation of visits from different professionals confusing and stressful (Moore, 2013).

TRANSDISCIPLINARY TEAMS

Transdisciplinary team practice means that the family and professionals work together as a collaborative team sharing information, knowledge and skills across disciplinary boundaries, with a key worker coordinating and doing most, if not all, of the intervention. Families themselves are valued members of the team and are involved in all aspects of the process. All decisions in the areas of assessment and program planning, implementation and evaluation are made by team consensus (Briggs, 1997; Woodruff and McGonigel, 1988).

Benefits of a transdisciplinary team include: a coordinated approach; service efficiency; cost effectiveness of services; less confusion for the family; more coherent intervention plans and holistic service delivery and the facilitation of professional development that enhances therapists' knowledge and skills building collective competence (King et al., 2009).

Role release is a feature of the transdisciplinary model. The key worker uses some direct intervention strategies from outside their discipline with supervision and support from relevant team members. 'Role release' allows the family to interact primarily with a key worker, who works in consultation with other team members, to create a coordinated service for the families. Through multiskilling and role release, all team members including the family develop 'shared meaning', which improves the effectiveness of the intervention for the child and family (Davies, 2007). However, this sharing of roles across disciplinary boundaries (and giving up) technical skills is the most challenging aspect of transdisciplinary practice because of perceived disciplinary boundaries and regulatory issues.

THE KEY WORKER

The Key Worker may be described as a Case Worker, Transdisciplinary Key Worker, Key Contact or Primary Service Provider. For this document the term 'key worker' will be used.

Research indicates that what parents prefer is a single point of contact with services and an effective, trusted person to support them get what they need (Drennan et al., 2005). An effective way to approach this challenge is to use a key worker model of service delivery (Alexander & Forster, 2012; Luscombe, 2010; Greco et al., 2004; Shelden & Rush, 2013).

The key worker acts as the conduit for the expertise of the whole team in most situations and uses transdisciplinary skills to do so. Where skills-based specialist intervention is required, the relevant team members should be involved. Although sharing many similarities with the transdisciplinary team model, the key worker model is seen as an enhancement of this model, but differs from the transdisciplinary model in some important ways (Moore, 2013).

The key worker focuses on working with significant adults in the child's life, imparting information, knowledge and skills to them by using coaching and consultation rather than only direct therapy with the child.

The key worker focuses on the child's natural learning environments using the child's daily routines and activities to promote the child's development and participation rather than working with the child solely in a clinical setting.

TEAM AROUND THE CHILD

The Team Around the Child (TAC) (Limbrick, 2001, 2004, 2005, 2009) is a teamwork model developed in the UK and has been adapted in Australia in a number of states. TAC is a systems way of coordinating early interventions for children and families who have complex needs and require interventions from a number of practitioners. The TAC model incorporates capacity building and evidence-based practices including: family-centred practice; strengths and interest-based practices; and the natural learning environment (Luscombe, 2010).

Features of TAC include: each child's key practitioners agree to work as a closely collaborative and well organised team; a key worker is the main point of contact for a family and is primarily responsible for coordinating intervention; families are equal and valued members of the TAC and are involved in all aspects of decision-making and intervention; support is continuous and seamless (Limbrick, 2005). As noted by the Victorian Government, 'there is a strong evidence base supporting the TAC approach as an effective way for a range of services to engage collaboratively and positively with families' (DEECD, 2014).

KEY FEATURES OF COLLABORATIVE TEAMS

Collaborative teamwork is a teamwork model that is flexible and combines some of the key elements of the transdisciplinary, key worker and TAC teamwork models into a workable model for today and into the future. It is easily understandable and identifiable for families and all the key stakeholders in ECI and the community.

Family members and professionals work together as a collaborative, integrated, coordinated team with the common goal of facilitating participation of a child and family in everyday community environments. Communication is crucial, contributing to problem solving, consensus decision making and other aspects of teamwork. Together team members develop shared: understanding, responsibility and vision.

Families are always central to the team and are the final decision makers. Other team members are invited, according to the specific needs and wishes of the family. Team members can include extended family, ECI service providers, private practitioners, ECEC educators, school teachers, paediatricians, and other adults whose skills and opinions make important contributions to the team. Over time, as the needs of the family and child change, team membership also may change.

A key worker, chosen by the team, coordinates information, services and supports. Family members sometimes assume the key worker role although, most often, they chose a professional to be the key worker. When the key worker is a professional, that person is the family's contact, providing much of the service to the child and family. Indirect work, such as coaching of the adults who facilitate participation of the child or family in everyday community environments, is a major form of service delivery. As the main service provider, the key worker must draw on the skills and knowledge of other team members.

Although not all team members directly provide intervention to a child or family, all share knowledge and expertise that informs implementation, planning and monitoring of services. A benefit of working in a collaborative team is the expanded knowledge and expertise that all members gain from sharing and reflecting with other team members. Shared knowledge and responsibility also contribute to a greater sense of satisfaction with one's work.

SKILLS FOR A KEY WORKER IN COLLABORATIVE TEAMS

A key worker as part of a collaborative team (and in the transdisciplinary, the key worker and TAC models who use a key worker), needs to have both expertise and experience in ECI practice to work effectively in the key worker role. They:

- work with families and other significant adults and apply evidence-based parent and parenting support using adult learning practices such as coaching and building on relationships based on trust and respect;
- need a sound base of the skills and knowledge of their own profession;
- require a sound understanding of child development, and;
- consult with other team members and children's services.

(Shelden and Rush, 2013; Alexander and Forster, 2012).

6. Capacity-Building Practice: encompasses building the capacity of the child, family, professionals and community through coaching and collaborative team work. The goal is to build the knowledge, skills and abilities of the individuals who will spend the most time with the child in order to have as great an impact as possible on the child's learning and development.

There was broad consensus across all ECI National Guidelines consultation workshops on the importance of capacity-building using principles of adult learning. Adult learning principles, which is the base of capacity-building practices is seen as a skills area that needs to be developed by the ECI sector.

Capacity-building practices support parents, caregivers, professionals and communities by using their existing abilities and developing new skills (Dunst & Trivette, 2009; CCCH, 2011). For families, this means that the ECI professional works in a collaborative partnership recognising what families do well already, and progressively building their capacity to meet the needs of their children and other family members. For early childhood professionals and other community partners, it means that the ECI professional builds on their existing skills, knowledge and abilities through coaching and collaborative teamwork which will then increase their capacity for working with the child with disability and/or developmental delay.

Capacity-building help-giving practices have a positive impact on a child's learning and development (Bruder, 2010). Children spend a very small proportion of their awake time in ECI activities (Bruder, 2010; Dunst & Bruder, 2006; Moore 2012). Therefore, it is essential to build the capacity of parents, caregivers and other significant adults who spend the most time with the child (Bruder, 2010). Capacity building practices are effective in increasing parents and caregivers' self-efficacy, beliefs of their parenting abilities - their sense of confidence and competence (Dunst & Trivette, 2009; Bruder, 2010; CCCH, 2011).

Coaching, which is a form of capacity building, is an effective way to develop parent/caregiver and educator capabilities and has been defined as: An adult learning strategy in which the coach promotes the learner's ability to reflect on his or her actions as a means to determine the effectiveness of an action or practice and develop a plan for refinement and use of the action in immediate and future situations (Shelden & Rush, 2010).

Coaching facilitates an exchange of information between the ECI practitioner and family and where the ECI practitioner and parent/caregiver or educator jointly problem solve and reflect on current practices and address challenging situations (Shelden & Rush, 2010). Coaching provides opportunities to learn and practice new strategies (Shelden & Rush, 2010).

ECI professionals need skills in communication and knowledge transfer – helping other adults understand and use what they know. These are the complementary skills of coaching, consultation and collaboration (CCCH, 2014). However, practitioners are not always adequately trained or prepared to work with adults and other practitioners either working in: the consultant's role (special education teachers and therapists) or as the consultee (parents, teachers and teacher's aides) (Buysse & Wesley, 2007).

When ECI professionals work together to support families/caregivers, early childhood educators and other community partners to achieve outcomes for the child, they are learning from each other through exchange of knowledge and skills. Networks are developed that can be accessed for future opportunities, hence creating a sustained strengthened service system to support families and children.

QUALITY AREA 4: UNIVERSAL PRINCIPLES

7. Evidence Base, Standards, Accountability and Practice: ECI services comprise practitioners with appropriate expertise and qualifications who use intervention strategies that are grounded in research and sound clinical reasoning. Standards based on these ECI key best practices will ensure ECI practitioners and services are accountable to continuous improvement and high quality services.

There was broad consensus across all ECI National Guidelines consultation workshops on the importance of universal principles. Participants felt strongly that the NDIS which involves a mix of private providers, not-for-profit service providers and government providers as well as new service providers that all professionals delivering ECI services across Australia adhere to a common set of national standards and accountability measures. These standards must be based on sound evidence and research.

Timely, accessible and equitable services for all families, in particular, vulnerable families is of particular

significance. Soft entry points to ECI services such as supported play groups, early childhood education and care services, child and maternal health services is critical. Referral processes that target Aboriginal and Torres Strait Islander families, culturally and linguistically diverse families and rural and remote families also are important for ensuring equitable services for all.

These ECI best practice guidelines based on strong evidence and research and supported by wide consultation across Australia were seen as an important first step to provide the base for further work in the development of standards for the ECI sector.

[1] Much of the available research and evidence in early childhood intervention originated outside of Australia. While the best practices espoused in this work resonates with Australian culture, there is a need for validation by research conducted locally.

EVIDENCE-BASED PRACTICE

'Evidence-based practice is a decision-making process that integrates the best available research evidence with family and professional wisdom' (Buysse and Wesley, 2006). In other words, evidence-based practice involves a balance of empirically supported interventions, clinical expertise or practice wisdom, and client or family values, preferences and circumstances (CCCH, 2014).

To ensure that they are working from a base of evidence informed by the latest research and practice, ECI practitioners should maintain knowledge and skills through lifelong continuing professional development. ECI also requires ongoing review and monitoring to ensure that practices are achieving the desired outcomes. ECI practitioners become more effective through critical reflection and a strong culture of professional enquiry (DEECD, 2011). Ongoing self-reflection, self-assessment and monitoring of practices are at the centre of the proposed development of practice standards.

THE ROLE OF DIRECT INTERVENTION BY SPECIFIC PROFESSIONALS

In addition to the body of evidence for the ECI sector there are also other bodies of evidence that suggest specific intervention for children with specific needs, such as cerebral palsy and autism spectrum disorder that lead to improvement in childhood development and skill development. This is particularly evident in disability- specific evidence. This evidence should be taken into account when providing services to young children. However, any specific intervention with young children should always be provided through the context of family centred principles, inclusive of coaching, and incorporated into everyday routines and settings. Therefore, providing ECI does not exclude the provision of specific targeted interventions, it is the way in which these interventions are provided and supported which is critical (ECIA, NSW Chapter, 2014).

LEGISLATION

Legislation underpins all the Best Practice Principles of Early Childhood Intervention. The UN Convention on the Rights of the Child (UNICEF, 1990) states that children with disability share universal rights with all people, and additional rights accorded to all children. The specific rights of children with disability are expressed in the UN Convention on the rights of persons with disabilities (UN, 2006). Among other international statements, the UNESCO Salamanca Statement (UNESCO, 1994) on inclusive education recognises the importance of inclusion of children with disability in mainstream education. Australia has its own legislation, at both national and state and territory levels, which supports both the rights of children with disability and the inclusion of children with disability (HREOC, 1986–2004).

QUALITY AND ACCOUNTABILITY SAFEGUARDS

A national consultation process to inform development of the NDIS Quality and Safeguarding Framework was recently completed. The proposed Quality and Safeguarding Framework aims to make sure the NDIS scheme will provide good quality supports and will maximise the choice and control of participants (NDIS, 2015). Under the NDIS, Governments will no longer be purchasing specialist disability services and therefore the current quality assurance arrangements and some of the safeguards will no longer apply (NDIS, 2015). This dictates a greater need for national consistency and a quality and safeguarding framework –that is mandating participation in an external quality assurance system.

Feedback received from the ECI sector and stakeholders during the consultation phase of the ECI National

Guidelines project overwhelmingly supported the need for an external quality assurance system as proposed in the NDIS Quality and Safeguarding framework. This option would require ECI service providers to undertake a rigorous quality assurance and improvement process to meet recognised industry governance and management standards and achieve certification/registration with a recognised certification/accreditation body.

TIMELY, ACCESSIBLE AND EQUITABLE SERVICES

The following four system problems were found to impact upon children with disability and/or developmental delay access to ECI services: lack of early identification; lack of easy access; lack of timely access and lack of full access (CCCH, 2011).

These system problems are linked to delays and waiting lists for assessments; lack of universal assessments; eligibility requirements; availability of services and practitioners and, in some cases, of culturally sensitive services and practitioners. The effectiveness of ECI is impacted both by the timeliness of identification and the timeliness of accessing an ECI service (CCCH, 2011; CCCH, 2004). Early identification leads to more benefits from ECI strategies targeted towards their needs (Bruder, 2010; KPMG, 2014).
 Research has shown that due to the nature of human brain plasticity, the earlier the intervention, the larger the impact on outcomes (Hadders-Algra, 2011).

Equity requires that each child, regardless of ethnic and cultural background, receives the support and resources needed to participate, engage and succeed. Families of children with the highest need for services are less likely to use them (CCCH, 2011). Soft entry points through non-targeted and non-stigmatised services, such as playgroups, provide a non-threatening setting for vulnerable and marginalised families to begin to engage with ECI services (CCCH, 2011).

Families with children with disability and/or developmental delay living in rural and remote areas lack information about the types of support that they need and are more likely to have difficulty accessing disability supports (Dew et al,. 2013). There is a shortage of therapists living and working in rural and remote areas of Australia (Dew et al., 2012; Dew et al., 2013; Fordham et al., 2012). This shortage means that families are significantly disadvantaged in accessing ECI compared with families living in urban areas (Dew et al., 2012). Further disadvantage is experienced by Aboriginal and Torres Strait Islander people as 46% live in outer regional, remote or very remote areas in Australia, and are twice as likely as non-Indigenous Australians to experience profound or severe restriction in activity and participation (Dew et al., 2012). Further challenges for families include: irregular outreach; distance to services; families' access to transport; and child care or respite care (Dew et al., 2012; Fordham et al., 2012).

One of the most significant challenges for delivering ECI services in rural and remote areas in Australia is recruiting and retaining practitioners (Dew et al., 2012). The lack of training, support, supervision, opportunities to work in a team, opportunities for career advancement and the amount of travel often required are difficulties faced by rural and regionally based practitioners (Dew et al., 2012). Access to continuing professional development and supervision and mentoring from experienced Allied Health practitioners can assist in retention of these practitioners and attract and retain new graduates (Lincoln et al., 2014). Research also suggests an increase in the use of technology and locally-based trained therapy assistants may improve access to services for families in rural and remote areas (Dew et al., 2012).

Outcome Based Approach: focuses on outcomes that parents want for their child and family, and on identifying the skills needed to achieve these outcomes. ECI practitioners share their professional expertise and knowledge to enable families to make informed decisions. Outcomes focus on participation in meaningful activities in the home and community with outcomes measured and evaluated by ECI services from a child, family and community perspective.

> *There was broad consensus across all ECI National Guidelines consultation workshops on this best practice. However, there were different levels of understanding in the workshops of what an 'outcomes- based approach' was and what constituted a 'functional outcome.' More work will need to be done by the ECI sector in developing these understandings and also in the assessment of the suitability of existing outcome measurement tools that ECI services can use to evaluate the effectiveness of their services.*

Outcome-focused approaches moves ECI services away from focusing on their service outcomes to focusing on the impact the service is having on children, parents/caregivers and families (CCCH, 2011). Outcomes are defined by Gavidia-Payne et al. as "those benefits that children experience in ECI programs so they become active and successful participants across a variety of settings" (2015). The three main outcomes for children relate to:

1. their social-emotional wellbeing;

2. acquisition and use of knowledge and skills; and

3. use of appropriate behaviours to meet needs.

Family outcomes are also considered essential to effective ECI service provision (Gavidia-Payne et al., 2015). Family-related outcomes include: increased sustainability of everyday routines; greater advocacy skills; sufficient family and social supports; decreased parental stress; increased family quality of life; greater empowerment; and more information about and access to other community services and resources (Llewellyn et al., 2010; Ziviani et al., 2010).

Outcomes should always be individualised and reflect the contextual needs of children and families. Increasingly outcomes are now set by families and are functional and meaningful for the child with disability and/or developmental delay and their family. Since families and other caregivers are the ones who will be seeking to incorporate interventions into their daily interactions with children, it is critical that they value the outcomes being sought. The process whereby the outcomes that will be addressed are identified is one in which the parents' views, values and circumstances are acknowledged, the professionals share their perspectives, and an initial set of outcomes that are valued by the parents are agreed upon (ECIA, NSW Chapter, 2014).

Focusing on functional outcomes and participation in meaningful activities builds on the intrinsic motivators of children and families and is, therefore, more likely to lead to success (WPPNE, 2008). A focus on outcomes provides ECI services with a basis for planning service delivery, allows flexibility to respond to individual needs and helps to identify the processes and data needed for monitoring, evaluation and continuous improvement.

To ensure that ECI services are effective, they need to measure and evaluate the impact of their strategies (Dew et al., 2014; CCCH, 2011). Outcomes being measured and evaluated should include both child and family outcomes (Bailey et al., 2006). The International Classification of Functioning Disability and Health (ICF) provides an important framework for assessment, intervention planning and evaluation of child-based outcomes (Cerniauskaite et al., 2011). Service provision should address all aspects of this framework, focussing on activity, participation and the environment. Ecocultural theory (e.g. Llewellyn et al., 2010) provides an important framework for considering the sustainability of everyday routines for families and in other contexts in which children participate. Ideally, service providers document both short- and long-term outcomes of services as well as factors that enabled or prevented delivery of the intended services (formative evaluation).

4 : CONCLUSION

The development of these National Guidelines on Best Practice in ECI is very timely as the introduction of the NDIS has provided the impetus for change and made it more important than ever to ensure consistent high quality ECI service is provided for families and their children with disability and/or developmental delay in this new competitive market-driven environment.

These guidelines and recommendations draw upon extensive consultation with the ECI sector and key stakeholders and from advice received from an Expert Advisory Group. The advice provided to ECIA during the consultation phase of the Early Childhood Intervention National Guidelines project was then cross-referenced against Australian and international research and literature in Early Childhood Intervention. So with these guidelines and the subsequent development of Standards for ECI, families and their children with disability and/ or developmental delay can be confident that the supports they access for their child will be of a high standard wherever they are located throughout Australia.

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