PRECI response to National Autism Strategy

1. **Strategy Overview:**
   PRECI supports the vision, goal, and guiding principles of the strategy, all of which are based on well-known and strong frameworks. We argue that a focus on ecological models of human development (Bronfenbrenner, 2005), would be beneficial as another foundation supporting the strategy. This framework would be particularly important in the design of policies and services as it focusses on the several contexts of influence on the lives of Autistic children and young people.

   Even though the strategy includes a statement on neurodiversity, none of the guiding principles acknowledge the multiplicity of other factors, including variability in neurodivergence, functioning, co-occurring conditions, and environmental contexts. Furthermore, recognition of First Nations and Culturally and Linguistically Diverse Autistic people as another key principle addressing the diversity found in the Autistic population is essential in the development of a comprehensive and responsive framework.

2. **Commitments:**
   PRECI supports the three commitments, as well as those related to research, evidence, evaluation and reporting covered in the strategy. However, they lack specificity and are largely generic 'motherhood statements', which can also be perceived as adult-centric. These limitations make it difficult to envisage how these statements can be translated into actions for Autistic children and young people if no activities and responsibilities attached to them are clearly identified. Some examples or priorities would be helpful to give an understanding of the expectations for each of these commitments.

   Further, the specific foci of the various commitments are ambiguous. It would be valuable to identify the 'objectives' for each of these commitments so that their intent is clear to all key stakeholders (Autistic children, young people and adults, families, service providers, professionals across a range of disciplines).

   1) Social Inclusion:
      - A more accurate definition of what 'social' is, needs to be addressed. In regards to young children, social development occurs as a result of their interactions and relationships not only with their peers, but most immediately with their families, and communities in activities and opportunities provided in play, sports and recreation. Considering these relational contexts, the experiences of Autistic children are intrinsically different to those of their adult counterparts, and as such they ought to be addressed specifically. Therefore, the strategy needs to include the notion

that support is required to ensure understanding of how to include Autistic children and that modification of activities will be most likely necessary to meet their needs in such activities. More importantly, this commitment would be much more solid if children's voices form part of the actions associated with a strategy that is designed to strengthen their social inclusion outcomes in all those contexts.

- Point 3 is unclear as to what section of the Australian government this refers to. Isn't this a commitment already in place?
- It is important to emphasise that societal norms and expectations often prioritise neurotypical behaviour and communication styles. These norms can create barriers to social inclusion for Autistic children, in particular, as their interactions or social needs may not align with conventional expectations. However, the obstacles to social inclusion and ways to overcome them are not specified nor addressed in this commitment. This is vital to the understanding and change of attitudes towards Autistic children across all of society.
- Providing examples of how to promote social inclusion for Autistic children e.g., focusing on creating environments that celebrate neurodiversity, accommodate diverse needs, and foster genuine understanding and acceptance is recommended.

2) Economic Inclusion:
   - This commitment is confusing in its aim - it brings together employment, careers, and levels of education. For example, it is unclear how advocacy resources fit in relation to students in education settings (point 10).
   - This commitment also needs to consider economic inclusion of caregivers of Autistic children. Families and caregivers are economically affected in a number of ways, most particularly losing income due to increased caregiving responsibilities for extended periods of time.
   - PRECI recommends that improving inclusive education in early childhood education and care, schools, and further education, should be a stand-alone commitment, and altogether separate from economic inclusion.

3) Diagnosis, Supports and Services:
   - The focus of this commitment on diagnosis and screening of autism and associated resources, at the expense of supports and services, may perpetuate deficit and medical notions of autism. It encourages the view that diagnosis is the only means available to access services and that this process can only be conducted by health practitioners.
   - It follows that consideration must be given to the different characteristics and profiles of Autistic children, some of whom may not necessarily require a diagnosis to receive services and supports. This means not only the early identification of such Autistic characteristics and other

neurodiversities, but also the timely provision of different levels of services by a range of practitioners in the education, health, and welfare sectors. This is not made explicit in the strategy.

- Understanding of the role of gender in the diagnosis and service provision for Autistic individuals is an important case in point when alluding to their varying characteristics. It is widely documented that girls, in particular, are diagnosed later compared to boys, and therefore struggle through their younger years being misunderstood and leading to additional issues such as mental health. We recommend that more education of a range of professionals and the community in general is required to understand autism in young girls so appropriate support is provided.
- This commitment is generally described as a 'professional' led commitment, where families' wishes and aspirations appear to take second place, particularly in the development and implementation of supports and services. Caregivers and families are not meant to just be 'involved' (point 12) but co-lead these activities for/with their children in a true partnership model. This means working together as a team with services supporting their Autistic children. Thus, the co-design statement in point 12 needs to consider caregiver voices in the early years, as well as caregiver voices for Autistic children with intellectual disability (profound autism profile) to gain a fair representation of the Autistic community.
- Point 13, 'resources informed by evidence' would more accurately describe what is currently in existence as opposed to 'best practice resources.'
- Point 14 could be much stronger, i.e., how does 'explore' constitute a commitment?
- Point 14b - how does it relate to foundational supports as stated in the recent NDIS review?
- Point 15 ignores the place of community (e.g., playgroups, childcare) and educational settings (e.g., preschool, school) in the early identification of autism. Furthermore, this point highlights health professionals (perpetuating a medical notion of autism), rather than thinking about the broad range of community-based professionals who can provide support in the early years of a child's life.
- Point 18, same as comment for point 13.
- Point 19 should consider support for parents of young children in making informed decisions about the most suitable supports for their children and families as they navigate the service system.

5. **Governance, research, evidence and evaluation and reporting.**
    - These areas appear to be afterthoughts and lacking in detail. A set of questions arise from this section as follows:
        - How is a culture of evaluation created among services?

- What kind of data is to be collected?
- What are the barriers and facilitators to gathering evidence? What settings are priorities for data collection? What are the key aspects of consistent reporting on outcomes?
- How does the evaluation and reporting strategy support and improve future outcomes for Autistic children and adults, particularly in relation to inclusion and participation and their quality of life in general?

It is vital that answers to these questions be provided in the strategy so that they form a considered approach to both processes and outcomes of research, evaluation and reporting.

6. Strategy Gaps: In conclusion

- PRECI supports the vision, goal, and guiding principles of the strategy, all of which are based on well-known and strong frameworks.
- A further guiding principle focussing on ecological models of human development would make the strategy more comprehensive, as would a principle acknowledging the diversity of experience of Autistic people and that of their family contexts. The latter, in particular, needs to focus on the importance of all government services working together to provide what is needed to build resilient families and communities (housing, health, education etc.).
- A revised strategy would benefit from increased breadth, depth, and specificity to effectively support implementation plans.
- Whilst the strategy states that concerns were raised with the Committee that "References to autism are often in relation to children only and do not recognise the experience of autism across the life span" (p 45), we suggest the strategy is adult centric. It does not give proper attention to the needs of young children with emerging developmental concerns or Autistic children and their families nor to the established evidence of the value and impact of early supports on a child's future experiences.
- At times, the document reads as deficit-oriented, particularly in relation to diagnosis, screening, and early identification.
- Inclusive education (from preschool to high school and tertiary education) is not included as a specific, separate commitment. Considering the school years cover a significant span in the lives of Autistic children, investment in this area must be a standalone commitment.
- Given that the implementation of the NDIS review recommendations will have implications for service provision for all Autistic people (with or without diagnosis), PRECI recommends that the NDIS review findings be an overarching consideration in the declaration of all commitments.

- A notable research gap refers to minimal representation of Autistic children and adults across all autism profiles. It is known that 80% of research in autism is conducted with or by Autistic individuals with IQs >70 or with good communication skills. Research needs to capture a diversity of Autistic individuals, namely Autistic children, caregivers, Autistic girls and women, and Autistic children and adults with profound autism or intellectual disability.

Reference:

Bronfenbrenner, U. (Ed.). (2005). *Making human beings human: Bioecological perspectives on human development.* Sage Publications Ltd.

Submitted on behalf of PRECI Board