Introductions:
- Emma Collin, Executive Manager: Marketing, Strategy and Policy
- Gill Pierce: Program Manager: Policy and Research.

Emma Collin:

- Thanks for the opportunity to present
- Congratulations on constructive reform proposals
- Carers Vic staff have read draft report with considerable interest
  - Still analysing content and recommendations
  - Staff gathering intelligence from participating in and presenting at a variety of stakeholder forums
  - Will make a further submission
- In addition, we are assisting Carers Australia with engaging caring families in forums to discuss the work of the commission which will assist Carers Australia’s submission development. We also encourage families to submit their views directly to you
- We are partners in the Every Australian Counts campaign and keep our members informed about both the work of the Commission and the activities of the campaign
- We plan to limit our discussion today to a small number of key issues which for us may be contentious. We also are keen to inquire about the origins of some recommendations
Issues to be discussed today:

- We believe there is potential for Australia to lead the way internationally by developing an integrated disability services system that is both person centred and family focused. This has implications for the proposed design of the NDIA, proposed funding entitlements and assessment and support practices.

- While high level policy and planning must address the needs of all people with a disability and their families, this may risk overlooking the key policy, practices and funding differences required for diverse individuals and equally diverse families.

- We challenge the Commissions view about separate supports for caring families- information and referral, counselling, respite and capacity building or training. Respite needs a different conceptualisation.

- We ask a few questions about the capacity of the market to provide.

- We will respond to the Commissions request for feedback on the desirability of including Carer Payment, Carer Allowance, Carer Supplements and Mobility Allowance into the NDIS.

- We will express concern about our understanding of proposals in relation to housing and support for people with a disability.

- We wonder whether proposed eligibility for NDIS and related data is excluding people with a psychiatric disability.
1. **An integrated disability system that is person centred and family focused**

- Most families recognise the interdependence and interconnectedness of the needs of the family with those of the person needing support and assistance
  - Know that adequate services for the PWD can contribute to an improved quality of life for families

- We argue that interdependence is the lived experience of most people with a disability and their families - AIHW data
  - 97% people under 65 with a severe or profound limitation live in the community. Of these
    - 84% live with family
    - 10% live alone
    - 3.2% with unrelated people, probably friends
    - Ongoing family support common after move to independent living.

- While overall objective of the draft disability care and support scheme is to enhance the quality of life and economic and social participation of PWD and their families, a person centred and family focused principle is not systematically applied in draft report.
  - An enlightened approach to disability rights shold be applied in relation to people with decision making disabilities and their families - (around 60% NDA services users) Substitute and supported decision making roles, direct family assistance with ADL’s, supporting communication and social participation indicate:
    - Need for increased support for those with significant level of ID
    - A need for joint planning / partnership as a family – with the NDIA and services providers
  - Degenerative conditions imply a need for progressive increases in formal and informal support. They are likely
to require progressive funding increases to support informal care. How will this be done?
  o The report does not address the barriers to workforce participation for carers such as the availability of substitute care, flexible work and financial barriers. (EMTR’s) Flexible work often means low paid, casual work.

- Disability rights movement and carer movement respectively have created a divide between services for the PWD and the services for their caring families, despite interconnectedness of needs. This has reduced the efficiency of services, increased costs, increased system fragmentation and increased the numbers of transactions/ agencies who need to be approached for support and assistance.
- There is potential to combine program funding for carers of people with a disability into a person centred and family focused disability system and thus;
  o Ensure a holistic focus on the person in their family situation
  o reduce the number of agencies involved
  o reduce competition for funds between stakeholders
- It is likely that individualised funding and the allocation of respite funding to the person with a disability will lead to a progressively reducing role for Carer Support Services as PWD and families minimise the number of intermediaries involved.

2. Diverse family needs

While high level policy and planning must address the needs of all people with a disability and their families, it may risk overlooking the key policy, practice and resource allocation differences required for diverse individuals and equally diverse families.

- There is no obvious intention to develop a layered approach to family entitlement – to accommodate families with differing needs. But there are many family circumstances where there is evidence of considerable complexity and risk to sustaining informal care. Examples:
  o Families who support and assist children or adults with very challenging behaviours
- Families providing high intensity ‘medical’ care for people who may be non mobile and require ventilation, PEG feeds, transfers and lifting.
- Complex care situations such as those involving young people with care responsibilities for a parent with a disability.
- Families who have multiple care responsibilities within or between generations.
- Sole carers/ single parents who lack informal support, are socially isolated and have few roles outside of the provision of support and assistance.
- Family carers who have disabilities or chronic illnesses themselves.

Tailored support for families at risk is required.

- Family support at transitions are important and a form of early intervention. Lifecycle and other transitions have enormous significance for people with a disability and their families. They include transitions from early childhood to preschool services, from preschool to school, from school to employment, further education or other adult services. They also include crisis care and transitions to care outside the family home.

In general at key transition points, both people with a disability and their families anticipate their future needs, collect information and explore available options, learn what will be involved, share the decision making as far as possible and consider what their new roles and responsibilities may be. Transitions for the PWD will commonly need to be timely, phased in and generally supported by families. Transition funding can assist this process. It should jointly focused on the PWD and their family.

- It is our view that funding entitlements need additional weightings for assessed family risk. (Prevention role)
- In addition, short term funding entitlements for transitions will be required – as will case management support.
- Our submission will include an outline of a model of carer assessment which can facilitate the identification of families who may require additional support.
3. **Respite and family support**

The draft report may misinterpret the need for respite support. This disguises a range of needed supports for the person with a disability and for their family. They arise in more complex care situations and in situations of change or risk as outlined above. A variety of regular ongoing and adequate disability supports, chosen according to needs and preferences, can assist in the provision of family support.

It is our view that a wide variety of services provide a ‘respite effect’ for the partners or parents of people with a disability. They can ensure that caring is shared. A respite effect can result from access of the pwd to adequate personal care, community access, in home behaviour management, education, day programs, employment, recreation and community participation, travel and holidays, if these are also tailored to the needs of families. Such tailoring can reduce the need for formal, more traditional respite programs. It can replace the notion of respite as relief of carer burden with positive opportunities for community participation by the person with a disability and for their caring families.

While there will always be a place for episodic and crisis support arrangements, the platform of adequate disability support, fundamental to early childhood intervention, can continue through the lifecycle.

4. **Can the market provide?**

- There are market distortions in community care in the form of undersupply for some high needs groups such as adults with cognitive difficulties and challenging behaviours; and people with profound and multiple impairments. ‘Cherry picking’ within the market can be demonstrated in relation to provider reluctance or refusal to provide services to the most vulnerable.

- The proposed NDIA will monitor service needs and gaps and there is a proposed innovations fund. Carers Victoria thinks that:
The initiation of new and responsive individual or group programs to fill gaps in the current services system will require infrastructure for community and program development. Will this be a function of the NDIA innovation fund?

While there are many benefits, there are also risks in individualised community access and participation – particularly the risk of isolation. Many people with decision making disabilities may wish to participate in new small group programs such as recreation and small group holidays. These may require block funding to seed their initial development, outreach and ‘back of house’ work.

How will community and program development occur?

5. Including carer payments and mobility allowances into NDIS?

We recognise the appeal of linking reductions in income support payments with NDIS. Cost offsets can then be used for more support for more people.

However, there is a fundamental misunderstanding in the PC report about the purpose of Carer Payment. It is seen as a payment for the care provided.

Centrelink defines “Carer payment is a payment for carers who, because of the demands of their caring role, are unable to support themselves by participating substantially in the workforce.” It is an income security payment, not a means of encouraging informal care, nor a choice for family carers.

Other income security payments are received by some caring families – aged pension, parenting payment, DSP.

- Need to comment on proposal that PWD may use carer payment as a means of choosing alternative options for informal care. Not currently precluded.
  - Disadvantages whole family – Newstart reduces income support.
- Risks undermining approp paid workforce –grey economy
- Can be an exploitation of payment recipient.
- Is potentially divisive for families.

In our view, this approach would commodify care and mask the difference between paid and unpaid care.

**Carer allowance, carer supplement and other payments**

Carer Allowance currently has an ambiguous rationale. Interpreted subjectively by carers, either as a form of recognition, or income supplement to meet costs of disability/caring. These are not met currently any other way.

Similarly Carer supplements are annual payments to carers to assist with the cost of caring, and child disability assistance payment and Carer Adjustment payment are payments for the cost of care.

CA and Carer Supplements remain important –and removal would be politically inflammatory.

Successful implementation of NDIS and increased workforce participation by carers may indicate a future need to review carer payment and allowance.

6. **Housing and support**

NDIS includes some housing types for some people, but not others. It is unclear what range and scope of housing and support models are included in ‘specialist accommodation support’. Other housing is seen as mainstream.

This may be problematic:

- While specialist accommodation and support must be included there may be a massive incentive to choose this option rather than mainstream housing, regardless of need or suitability
• It is inequitable in that housing is being provided on the basis of disability type and assessed support needs rather than housing needs. This excludes people with some forms, and levels of, disability, over others.
• Lack of access to housing is about income (due to disability), affordability and lack of supply. See earlier questions on notice.

Carers Victoria is concerned about the impact of lack of suitable housing on the NDIS. The capacity of the NDIA to lever improved supply of social housing and address access barriers will be crucial.

7. We wonder whether proposed eligibility for NDIS and related data is excluding people with a psychiatric disability