RESPITE:

What is it and what does it do?

Respite is an alternative support option for the carer to access, which sustains the continuity of care for the care recipient while the carer is unable to directly provide this support themselves. It enables the carer to have a life and lifestyle choices outside of their caring role.

While this is similar to the definitions already given, it is fundamentally different with regard to the purpose and outcome.

Direct Respite - is as per above definition.

Indirect Respite - as currently outlined should be removed and replaced with the title of 'Carer Support' or something similar. 'Indirect' respite reduces the burden on carers to meet all the activities of daily living while continuing in their caring role. It is not respite however.

Planned Respite – Enables the carer to plan in advance for periods of time when they can address their own health and wellbeing needs outside of those of the person they are caring for. This 'Right' is acknowledged within the Carers Recognition Act 2010.

Emergency Respite – A support option for carers to access at times where an unplanned and/or crisis event has occurred, and where an immediate and short term response is required.

What else is it?

Respite is one component of effective carer support.

What isn't it?

Respite isn't something that occurs for the carer while the care recipient is having a therapy session or attends a day activity or something else. This is a complete misnomer.

The outcome for the carer in this circumstance (recognising that often the carer has to take the care recipient to the activity or therapy session and pick them up later and importantly that not every care recipient has a full-day activity schedule) is that they have time to do the shopping or pay the bills or clean the house, or do the washing etc. In short, it enables the carer to do all the other activities of daily living while the care recipient isn't with them. None of this however addresses the overall health and wellbeing of the carer nor does it enable the carer to have a life outside of their caring role.

What does Respite mean for the Care Recipient?

The outcome for the care recipient is that the continuity of care is sustained in the absence of the carer.

Who benefits?

Both the carer and the care recipient. They are linked by outcome.

Concerns/Issues:

- The directions and focus of the NDIS and CHSP reflect on the extent and quality of support for the care recipient. I see no such similar quality outcome or focus for the carer anywhere in this current direction, yet everyone says they recognise the role that carers have and also what would happen if the carer could no longer continue to care.
- The current directions re: respite within the NDIS which is to remove it completely, leaving it unrecognised and therefore unfunded, (including the ILC)., completely devalues carers and the need for support in their own right outside of their caring role. There is no assessment of carer need anywhere within the NDIS or CHSP Processes.
 - Therefore this outcome, coupled with the loss of dedicated carer support funding to the NDIS and CHSP, has and will continue to result in the extent, nature, frequency and availability of dedicated carer support to the carer being completely dissected and lost. I believe the work being done now to develop an integrated carer service, including the establishment of the Carer Gateway, flies directly in the face of this outcome. So how can the transition of carer funding to the NDIS and CHSP continue to happen? Something isn't right in this equation.
- There are too many diverse carer scenarios to neatly and effectively fit them all into 'packages' where the outcomes are focused on the care recipient. This isn't saying that the two aren't linked because they are and can be. It is saying however the reasons behind why carers require support in their own right differs to that which binds them to the continuity of care and support required by the care recipient. Further, how will the ongoing recognition and support for young carers, carers from a range of CaLD Communities, Aboriginal carers, working carers, and carers from all of the other unique communities that exist, be addressed within this direction. I suggest they can't.
- It seems there is too much focus on definitions rather than on outcomes and what those outcomes are. It seems that we are trying to have an each way bet on; is it for the carer or the care recipient. Sometimes it simply can't be for both. <u>Carer support</u> is just that.

Peter Sparrow April 2016