My thoughts on the carer gateway draft paper design considerations are as follows:

There should definitely be a central intake which could also be integrated with DHHS. It should be mandatory, however the ability to opt out should be available upon request of a healthcare professional to protect the carers who don’t see their needs initially. The needs of carers are intertwined with the needs of the person they care for and it makes sense to identify the needs of the care recipient and the carer along with the ability of the carer to meet the care recipient’s needs. The carers need to be taken care of along with those to whom they provide care for. Also, reviews of both should coincide. By assessing both together, the process is streamlined, cost effective and takes into account all relevant information, a simple checklist could be created to make sure everything is covered. The carers should be registered (along with an emergency care plan) at the time of diagnosis even if the carer is unaware of their needs or what assistance is required. This will then need to be reviewed and appropriate action, if any, taken. Reviews can be as simple as an email or phone call once a year asking a carer to log onto the website and check that the information is current and the checklist questions. Frequency of reviews can vary according to needs. Carers do not focus on themselves and may think supports are unavailable or they may not see the relevance until there is a crisis. Assessing and reviewing together will mostly overcome the carer’s reluctance to identify their needs as they overlap with the care recipient. Sometimes alternate supports need to be offered either in place of something unavailable or to better assist the carer in the caring role. There must be flexibility of funds to provide required supports to meet needs and overcome problems, it shouldn't be restricted to fit strict government guidelines. I feel the carer’s needs and ability to care should form part of the NDIS in order to help keep carers caring. The relationship between the NDIS and carers needs must be explored.

Any carer gateway should have easy access allowing carers to log in and look for relevant information, bookmark service information, and maybe book a course or contact a peer support group. There should be an app for that! I believe a central online and phone system would be beneficial for many carers where different supports are outlined and accessibility highlighted, similar to an airline or hotel booking system, online shop or Centrelink page with options to explore and relevant links.

Education for the carer helps them to help themselves and has been shown beneficial, so this should be offered at every opportunity, online would suit some and be cost effective. Education should also be offered with counselling and coaching. As each carer and their needs are different, there is no one size fits all, so any programme needs some flexibility. Carers can be offered courses while they wait for assistance or it could be made part of the assistance to ensure that carers take up the option, but discretion is required. All healthcare professionals should assist in the education roles where possible, either by giving tailored advice or demonstrating what the carer needs to know in order to care. It could be as simple as showing how to put on compression stockings or lift someone from a fall, or there may be more complex needs. When individuals are with healthcare professionals, the needs are discussed and this is the time to tailor advice according to needs. A simple handout with information can be useful and cost effective. Again, the healthcare professional should refer where assistance is required.

For peer support groups, these should start with a facilitator and then the group can elect a leader to run meetings with visits from facilitators/experts or if group numbers decline, groups can merge. Coaching and counselling is only suitable for some, and it should be available in many forms, including ad hoc. Keeping costs down by using technology is smart although not suitable for everyone even though many carers may prefer phone or online contact, so give them the option. Common sense must always prevail.

Goals are not always necessary and self assessment is often sufficient, different solutions for different circumstances, flexibility is required. Many can handle funding, whilst others cannot or find it adds burden to the caring role, individuals need to be assessed. Carers can be easily overwhelmed or even depressed and this makes it difficult for them to recognise their own needs. Carers must be open to support so timing is crucial, this is why it is important to ask often. Unintended effects can be mitigated by tailoring to individuals needs.

Carers have varying needs at varying times, it seems logical to review the carer upon request and at the same time as the care recipient to asses the needs of both individuals. This will aid in supporting the care recipient and the carer whilst supporting the carer in their role. There are natural times where care needs can be assessed and reassessed, such as diagnosis or change in circumstances. I really believe there should be a mechanism where the carers needs are considered along with the care recipient’s needs and the carer’s ability to meet those needs. I acknowledge that not all carers need supports, but even those not wishing to identify as carers should be given opportunities to identify their specific care needs. For example a doctor or therapist may ask how the carer is doing or if there are any difficulties and then refer them on when reviewing the care recipient. Every healthcare professional is an opportunity to engage whether it be at a local clinic, rehab or hospital.

The barriers carers face must be recognised. We often feel like no one listens, no one takes us seriously, no one cares and no one understands. We are often mentally exhausted and disrespected. We are all time poor and often in financial hardship. Access to services can be hard and costly and formal respite services may not suit, a day programme runs certain hours which may not suit an appointment or an engagement or even a funeral. Carers have multiple responsibilities and this impacts on their health and wellbeing. The caring role often prevents them from looking after themselves. Something must be done to avoid carer burnout. The risk of crisis is real.

Also, information must always be a two way street. There are many opportunities for any healthcare professional to engage with a carer and these should be utilised; a carer may take the care recipient to visit a healthcare professional who could then provide relevant information, suggest a course or ask if there are any issues, even if the issue is unrelated, the healthcare professional could suggest to seek help elsewhere. There needs to be a system where touching base is the norm at natural opportunities as this is cost effective and should eliminate those who usually fall through the cracks.

There is no one size fits all. We all have different needs.

The most cost effective solution to reach all is to employ current supports to ask if there is a need and then refer to a call centre or website.

There must be innovative, flexible and tailored support.

Formal respite may not suit or be affordable.

We must avoid carer burnout.

Carers need to be supported and educated in their roles to avoid impacting on their wellbeing and that of the person they care for.

Access should be easy, not a web of red tape.

Carers needs are often overlooked. For example, I've had difficulty obtaining a dental appointment around my disabled son’s school hours. My son, having a disability, is entitled to care without waiting (priority access is given to some including the disabled, pregnant women and even refugees, but not carers). Something as simple as adding carers to the priority list would be of immense assistance and recoginze difficulties faced by carers all whilst avoiding costly respite. If the carer cares for some one with a registered disability, it would follow that they also would need extra assistance. Nobody seems to recoginze the extra difficulties carers face, it's disheartening to try to make an appointment around care commitments only to have some one tell you that you're being difficult when the fact is that it's your life that is difficult and you have to always ask that others understand and assist instead of labelling you as difficult - we’re not difficult, we just live in difficult and extraordinary circumstances.

Thank you for your time.