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| **Attendees**: Tina Lincoln (Care Matters), Shane Doull (Kitchen Table Whanganui), Wai Campbell (Kitchen Table Whanganui), Wendy Brenkley (Complex Care Network), Christine Zander-Campbell (Parent to Parent) and Rebecca Walton (Development Manager and Secretariat Support – Care Matters). |

**Apologies:** Dr Carey-Ann Morrison (Imagine Better), Katrina Fletcher (Carers NZ) and Kellyanne Tong (NZDSN),

**General Update**

1. Update from Advisory Group members.
2. Update from Tina Lincoln on the Mid-Central prototype.
3. Discussion of action points from the previous meeting (the EGL pamphlet was not added to the Care Matters website as Rebecca could not locate a digital copy).
4. Update from the Development Manager on Care Matters (ie. annual work plan, resource development, reporting and survey results, etc.)

***Summary of results and achievements***

At the current time, we have completed 35 of the 37 workshops and all 12 resources (for this 12-month period).

The resources completed include:

*SAMS*

I CHOOSE, The Kaituhono/Connector Role, EGL/System Transformation Update and Transition for life (the Early Years, Middle Years, Adulthood and Getting Older workshop power points) and Transition for Life (webpage), Advocacy & Supported Decision Making and Teaching the Teacher Aide (in development).

*Parent to Parent*

Interactive personal budget tool, ASD booklet and 4 podcasts (ie. interview with the Minister for Disability Issues, two podcasts on Mana Whaikaha and one podcast on anxiety).

The average number of people attending workshops (to date) is 14. Participants reported 100% good, very good or excellent satisfaction at these events (please note most of the results were either very good or excellent).

A six-month mid-point survey was conducted in May. Results are similar to previous surveys; these results will be added to the October survey and a report written based on analysis of the 12-month period from 1 September 2018 – 31st August 2019.

For the first six months of this contract period the six resources that have been viewed the most on-line are:

* The Middle Year’s (Time-Line)
* The Early Year's (Time-Line)
* EGL Overview
* IRRS – applying for government subsidised rent
* Home Ownership guide
* Individualised Funding/Respite

The four booklets in the Time Line series are still proving to be the most popular resources on the website (the Early Years, Middle Years, Adulthood and Getting Older). These were the resources the original e-leadership group and other carer networks suggested needed to be developed.

A joint project with PVI (Parents of Vision Impaired) saw Care Matters staff create four workshop power points that covered key stages and transitions throughout life. By the end of August, three workshops will have been held on *‘Transition for Life’* (two in Wellington and one in Christchurch). This is a new partnership developed over the last 12-months.

***Discussion Points***

*Hui in Palmerston North* - for “Toku Reo – Toku Oranga” wananga on the 20 – 22nd August 2019. This is being organised by Wai and will have a several themes, including feedback on evaluation and the Mid-Central prototype.

*Terms of Reference* – a clause has been added to the Terms of Reference about changing advisory group members. Advisory group members discussed the policy for the renewal of advisory group members and succession planning which will be discussed in more detail at the next meeting.

*Database usage* – discussed how the database was set up and how it can be used. Additional advertising (material sent to Care Matters that might benefit families) will be advertised on the Care Matters Facebook page (which is currently under development) rather than through the database.

It was also acknowledged that Care Matters needs to have a variety of communication methods other than through social media. All workshop information is sent out through emails and workshops can also be advertised through the Care Matters Facebook page. Other suggestions included

Edu blogs, Loomio or Coactive.

*Vision Planning* – the Advisory Group had a brief look at the mission and vision of Care Matters. The group decided to try and find funding so that the Advisory Group could spend one or two days looking at the vision, developing partnerships and strategic planning. Rebecca and Wai to look at avenues for funding in consultation with the SAMS CEO, and Board.

*Partnerships* – one of the organisations that was suggested for Care Matters to develop partnerships with is Oranga Tamariki (Wai to pass on contact).

*Sibling Project* – put on hold. This is still an area needing resource development for the Care Matters website.

*Teaching the Teacher Aide* resource – the Advisory Group provided additional feedback for this resource.

*Taha Wairua Mauriora Whānau (video) –* this video was viewed by the Advisory Group and the group acknowledged the great content and work that had gone into this.

*Carers Strategy* – the Advisory Group went through the carers strategy and looked at any feedback they might provide. The carers strategy is an important guiding document and helps direct resource development.

The group felt that the language was out of date and did not reflect the language used in EGL or Whānau Ora. They also felt that it did not recognise lived experience. Feedback to be provided on the Carers Strategy and individual submissions are encouraged.

**Annual Work Plan**

The five areas prioritised for development for this 12-month period by the Advisory Group are:

* Purpose Built Service – for those families who want to build a service around their family member using a personal budget – how do they do this? What’s out there to assist them? Examples of other families and what they have done? Templates to assist families?
* Disability & Mental Health Interface - information on how to navigate the system when your child receives services from both disability support services (DSS) and mental health services (DHB). How do these work together in a way that benefits me and my family? How can I get them to work together? What support can I get? Tips/stories from other families in similar situations…..etc.
* Siblings – need for specific resources for siblings, including resources on the website (specific to siblings) and a resource that has a Future Planning focus (as parents’ age).
* Expectations of families in the new era – how should providers be responding to families? What can families expect? Building on resources about System Transformation - and expanding/updating what this will mean for families.
* Respite – this is a major concern for families and families want more information/ideas of how to make this work. What are people doing? How are they doing it? How do they make housing work (shortage/not enough/not suitable)? Need to include a Kaupapa Māori service (and what they do).
* In addition – need to check workshop/website resources are up-to-date.

*Additional areas for development include:*

*Note: Care Matters keeps a list of potential resource development ideas from carer networks which is continually updated and prioritised.*

*Welfare Guardianship*

This can be a very complex process for families; it would be good to have some tips on how to do this as it can be a costly and confusing process. If we develop this further, it was suggested the Advisory Group contacts the president of the Law Society (Tiana Epati) and discuss some of the issues raised.

*Develop an app for a cell-phone or iPad which ‘navigates’ the disability* *sector*

The app would provide a guide to the various agencies and supports that are available. Ideally it could be like google or Facebook algorithms that the more you look at a topic, the more information or guidance you receive on that topic. It could broadly cover (with links within links to burrow deeper) supports from Ministries of Health, Education and Social Development, System Transformation, EGL, Work and Income, ACC, DHB support, mental health support, physical/intellectual disabilities, sensory disabilities, behavioural disabilities, aged care supports, etc.

*Older Parents – Strategy*

How can Care Matters meet the needs of older parents? How can we educate/inform parents and older adult siblings about System Transformation, EGL principles and Planning for the Future? Often older parents identify as the caregiver and this is a significant/meaningful part of what they do/who they are. This will be discussed in more detail at the next meeting.

**Action Points:**

*Annual Report* – send the Annual Report (with the Advisory Group notes from this meeting) to the Advisory Group members.

*Vision Planning* - Rebecca and Wai to look at possible avenues for funding to spend one or two days looking at the vision, developing partnerships and strategic planning for Care Matters, in consultation with the SAMS CEO and Board.

*Oranga Tamariki* – follow up regarding building a partnership (Wai to pass on contact).

*NZDSN representative* – Rebecca to follow up with Kellyanne Tong about her replacement.

**To discuss at the next meeting:**

*Terms of Reference* – to discuss at the next meeting the plan for the renewal of and succession planning for the Care Matters Advisory Group members.

*Older Parents Strategy* – to discuss in more detail at the next meeting.

*Development of an app (Wendy) –* look at possible strategies – what this might look like and how this might happen? Rebecca to bring stock take of what Care Matters already has on its website and what other websites offer.

*Navigating vehicle modifications (Wendy)* - it appears to be dependent on age, whether you are working, who will pay for the assessment, do you qualify for lottery welfare, etc. NB: I think it would be useful for an algorithm to navigate the system for those unable to use public transport, an unmodified vehicle or standard mobility taxi.

*Welfare Guardianship* (Wendy) – see notes.

**Next Meeting Date:**

**Monday the 17th of February 2020, 10 – 3pm, in Palmerston North** (same venue).