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| **Attendees**: Tina Lincoln (Care Matters), Shane Doull (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:** Wai Campbell (Kitchen Table Whanganui, Dr Carey-Ann Morrison (Imagine Better), Katrina Fletcher (Carers NZ) and Kellyanne Tong (NZDSN),

**General Update**

***Update - Mid-Central Prototype (Tina Lincoln)***

* The baseline survey is on the Mana Whaikaha website.
* The first phase of the developmental evaluation has been completed (the report is in the final stages of sign-off). The Try-Learn-Adjust group have made recommendations for the Governance Group to consider, who will formulate recommendations for Ministers.
* The new transformation lead from MoH is James Poskitt.
* There is no announcement yet for post June 2020.
* Providers are working together to respond to crisis.
* Not enough Connectors to meet demand.
* No direction from MoH about the 2nd Baseline Survey or the 2nd phase of the Mana Whaikaha Mid-Central Evaluation.
* All Regional Leadership Group minutes are on the Mana Whaikaha website.

***Update - Summary of Care Matters results and achievements (Rebecca Walton)***

At the current time, we have completed 12 of the 37 workshops for the period from 1st September 2019 to August 31st 2020.

The Advisory Group were provided with a summary of results from:

* Annual Report (1st Sept 2018 – 31st Aug 2019)
* Resource Development for current reporting period
* Annual Survey Results

The average number of people attending workshops (in the previous year) was 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). There was a 13% increase in the number of workshop attendees and a 94% increase in the number of people who have accessed the website.

The annual on-line survey results (which had a 10% response rate of the total number of workshop attendees) reflected the feedback from the face-to-face workshop evaluation forms.

Overall on average 95% of all participants (from both the on-line survey and workshop feedback) rated workshop satisfactions between good, very good and excellent. Overall the feedback was very positive with some improvements noted by a couple of attendees.

Tina provided an overview of some of the workshops and Kitchen Tables completed around the country, this included Levin and Foxton where Tina has been piloting ‘A Tailored Life’.

***Resource Development***

Since Care Matters started there has been 75 resources uploaded to the Care Matters website, 70 of which were produced for Care Matters (some through projects such as the ‘Think Differently Campaign’). There are also 10 additional links on the website to other key websites/resources produced by other organisations.

The Advisory Group prioritised the following five areas for resource development for this 12-month period:

* Building a Purpose-Built Service
* Expectations of Families in the New Era
* Disability and Mental Health Interface
* Siblings
* Getting a break (respite)

SAMS is looking to produce resources in the following areas:

* Building a Purpose-Built Service (A Tailored Life)
* Expectations of Families in the New Era
* Disability/Mental Health Interface
* Getting a break (focusing on stories)
* Translating key workshop resources to webpages

A number of new workshop resources have been created, some of which will be translated to webpages, these include: A Tailored Life, Families Preparing for the New Era, My Network, Advocacy, and Communication (what happens after DESC).

Several workshop resources have been updated and these include: Education, Resilience, Stress and EGL System Transformation.

Parent to Parent will focus on the following resources:

* A resource addressing sibling needs across the life course (childhood, the teen years, adulthood, older years).
* Self-advocacy toolkits for siblings aged 8-12
* Self-advocacy toolkits for siblings aged13-18.
* Legal issues video aimed at adult siblings.
* Practical tools for parents to support siblings experiencing anxiety. This builds on feedback from our anxiety workshops
* TBC - Video featuring parents who have developed their own service for their family member without EGL but aligned to EGL principles. Or resource addressing the power of visioning and tools such as PATH and MAP that are in widespread use.

***Vision Planning - PATH process***

Care Matters is funded by the Ministry of Health and this contract is up for renewal at the end of August 2020. With this in mind, the Advisory Group looked at Care Matters future direction, goals and vision.

This process involved using the PATH process to gather feedback from the Advisory Group and staff, to look at what we are doing now, and what we would like to be doing within the next couple of years. All the information gathered will be collated and presented to the CEO of SAMS and the SAMS Board.

In summary, the key focus areas for the Advisory Group included:

1. **Presentations to other key groups** (ie. organisations working with families - professional bodies, not-for-profit trusts, government funded organisations and departments, etc …)

Having the ability to present to a wide range of groups (ie. DHB’s, Oranga Tamariki, pediatricians, school boards, psychologists, service providers, polytechnics, support workers, etc).

Care Matters is funded to work directly with families and not with other groups. The Advisory Group sees a significant benefit for families in being able to speak with these groups - particularly those who work directly with families. Our experience is that groups are often not aware of:

* the ‘needs’ of families (ie. stress/crisis/support needs, etc.)
* the various disability supports and services available for families
* the on-line resources available for families (ie. the Care Matters website), and
* EGL principles and the needs of families in the ‘new era’.
1. **Workforce Development**

Are their ways we can assist with workforce development for families or for their disabled family member? Care Matters has the experience and expertise to provide advice on planning, setting up tailored-made-services, training of staff, training in EGL principles and how to design a service around this, managing personal budgets, etc. This is an area for Care Matters to explore further.

1. **Meeting the needs of diverse carers**

The Advisory Group discussed who typically attends workshops, where the gaps are, and how we can meet the needs of those who aren’t the typical attendees. Some of the focus areas include: Pasifika, Māori, young families, and fathers.

Different groups may need different strategies, especially those who may be in crisis, unable to leave their family member, have a new diagnosis and are not aware of the supports available, or those who typically would not attend a traditional workshop.

The group discussed how Care Matters could provide information in different or innovative ways, which included the use of technology, developing on-line modules, using Zoom for follow up for Kitchen Tables, and using an ‘outreach approach’ instead of a ‘workshop approach’.

1. **Resource Development**

Resource development continues to come from the diverse carer communities we engage with. The key focus for the Advisory Group is the gap in resources for families who interface between disability and mental health services. There is a significant gap in resources and professional support to assist families to navigate this area.

1. **Leadership Development**

Care Matters has provided opportunities for people to gain practical leadership skills through an internship programme (funded by Te Pou). The Advisory Group would like to see a Leadership Development programme become part of Care Matters ongoing core business.

***Discussion Points***

*Terms of Reference:*

Every two years, every Advisory Group member needs to confirm their continued attendance (ie. this may require discussion with the organisation they have been appointed through).

It is important that there is diversity within the Advisory Group members so that there are a range of different voices around the table (ie. family members from different carer networks and those appointed from other organisations).

The agenda will include a quick check of people’s continued availability to be part of the Care Matters Advisory Group, so we can succession plan.

*Additional areas for development:*

The Development Manager went through the resource development ideas provided by different carer groups/networks (over the years) and what is still outstanding.

Care Matters keeps a list of potential resource development ideas from carer networks that is continually updated and prioritised. This list is discussed when prioritising resource development for each year.

*Wellbeing Resource:*

The group discussed the potential need to have a separate wellbeing resource. At the moment Care Matters has information linked to this topic, but these are embedded in a number of different resources.

It would be useful to have this information more easily accessible. Christine is aware of and has access to a range of useful resources that could be linked to the Care Matters website (ie. ‘Just a Thought’, 5 ways to wellbeing, booklet of apps, mood diaries, sensory box, etc.). Rebecca to do a ‘stock take’ of what we already have on-line and look at how to make this more accessible for carers to find.

*Current Resource Development:*

Discussed potential resource development options around *‘getting a break’* and what that could look like.

The resource for ‘Disability & Mental Health interface’ was also discussed. A meeting date was organised so that Lianne Clarke (Project Lead) can meet with Christine to discuss the outline of the resource and development process.

*Legalised Marijuana:*

There are two key New Zealand referendums during 2020 – the cannabis referendum will be a non-binding referendum, held at the same time as the 19 September 2020 general election on the question of whether to legalise the personal use of cannabis. A euthanasia referendum will be held at the same time.

It may be useful for families to have some links to information regarding these referendums added to our news section. Any links to the Care Matters website needs to be from reputable sources that provide information without bias.

**Action Points:**

*Vision Planning* - provide the Advisory Group with the final version, look at priorities and the Care Matters work plan going forward.

*Advisory Group members* - find replacements for Advisory Group members where needed.

*Renewal of Contract -* set up a meeting and discuss the renewal of our contract with MoH.

*Wellbeing Resource* - look at what information Care Matters has, what needs to be added and how it can be refigured so it has its own page.

**Next Meeting Date:**

**Monday the 27th of July 2020, 10 – 3pm, in Palmerston North** (same venue).