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| **Attendees**: Wendy Brenkley (Complex Care Network), Tina Lincoln (SAMS), Christine Zander-Campbell (Parent to Parent), Dr Carey-Ann Morrison (Imagine Better), Wai Campbell (Kitchen Tables), Katrina Fletcher (Carers NZ), Rebecca Walton (Secretariat Support – Care Matters). |

**Apologies:** Mark Benjamin (SAMS) and Jenny Hoskin-Wyber (NZDSN)

Note Taker: Rebecca Walton (Care Matters)

***Update & Previous Agenda items:***

1. Rebecca provided the group with an overview of Care Matters, its purpose, vision and the previous work completed.
2. New Advisory Group members were welcomed - Wai Campbell who is involved in the Whanganui Kitchen Table group. Dr. Carey-Ann Morrison who replaces Sue Robertson and Katrina Fletcher who is the new Carers NZ representative.
3. Confidentiality agreement signed by Advisory Group members. The confidentiality agreement ensures that any personal information is not shared, outside of the group, without prior permission to do so.
4. Carers Strategy Reference Group – Rebecca to follow up with Laurie regarding an invitation for an Advisory Group member to speak at this group.
5. The Care Matters annual survey was completed in October of 2016 – a random sample of workshop participants was selected for a follow up phone interview on their experiences with Care Matters and the workshop/s they attended.
6. Advisory Group meeting notes and the Terms of Reference can be found on the Care Matters website.

***Discussion:***

1. **Prioritization of resources (to be completed by Sept 2017)**

* *Time Line (7 – 13)*

The second section of the time line (7 – 13). The time line has been broken into five sections (0 - 7, 7 - 13, 13 - 21, 21+ and Getting Older). The first section (0 - 7) was completed in 2016.

* *Treaty of Waitangi*

To include on the website a resource that provides information about the Treaty of Waitangi and incorporates a real-life example or story of how it can assist families today. Include a link to a list of iwi providers.

* *Cultural and diverse realities*

For the Care Matters website to include a cross-section of culturally diverse stories that a range of families (in different circumstances) can relate to.

This could include stories on what ‘respite means for me and my family’ and be linked to the Kitchen Table project/s or to another research project.

* *Mapping Educational Opportunities*

To include tips from families about navigating educational opportunities for their children/young adults. This would include key transitions and advice on typically asked questions. MOE has a flow chart and IEP guidelines which could be attached to this resource.

* *How do we keep families strong?*

To look at capturing the voice of fathers, including information for siblings, resilience, what helps families remain strong, etc. NB – this ties into the two videos that will be produced by Parent to Parent on siblings.

1. **Advisory Group Representation**

Advisory Group members are nominated from a number of different carer networks/disability organisations so that a diverse range of view points are represented. 50% of current members are in non-paid roles and are either linked to, or members of, the groups that nominated them (ie. Complex Care Network).

Nominations are based on the skills and experiences that different nominees bring to the Advisory Group. Advisory Group members “participate … in their own right as leaders and do not represent any one perspective” (Care Matters Terms of Reference, number 8).

Each Advisory Group member will provide a brief profile and photo that can be added to the Care Matters website.

The Advisory Group discussed what possible ‘conflict of interest/s’ there might be. Any potential conflict of interest needs to be addressed at “the earliest possible time” … “with the parties concerned and steps taken to manage these conflicts on a case by case basis” (Terms of Reference, number 18).

1. **Feedback**

The Advisory Group welcomes all feedback - feedback can come through a variety of means – by contacting Rebecca Walton who oversees the Care Matters contract with the Ministry of Health ([samsrw@outlook.com)](mailto:samsrw@outlook.com)), through Advisory Group members and their associated carer networks and the e-Leadership Group. Feedback is also gathered through workshop feedback forms and annual surveys. All feedback is used to strengthen Care Matters.

1. **Brochure**

The Advisory Group looked at the DRAFT Care Matters brochure. The brochure is being funded by the SAMS Board. The Advisory Group made some suggestions and these changes will be circulated to Care Matters staff and Facilitators for comment. Once finalised these will be printed and made available for distribution.

1. **Proposal for new videos (Parent to Parent)**

Parent to Parent presented a proposal for the two video’s that are funded by the Ministry of Health under the Care Matters contract. These videos are to be completed by Sept 17. The two videos will be based on themes to do with siblings.

Possible themes discussed the Advisory Group include:

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| * relationship with parents and other siblings (including different ages/roles and expectations) | * dealing with difficult questions/what helped when things got tough? |
| * using strength based language | * forward planning (as parents age) |
| * how to deal with bullying | * strategies to assist with looking after yourself (including resilience and mental health) |
| * having siblings from different cultures sharing their experiences | * using humour – (ie. “what *not* to say to your ADHD child”, etc) |
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1. **Promotion of Care Matters**

The Advisory Group discussed possible ways to promote Care Matters and increase the number of people who are aware of Care Matters and the workshops/resources it provides:

* Disability and Health Advisors (DHB)
* Communication Officers (DHB)
* Health Authorities (newsletters)
* TV add
* Wellchild books (Plunket)
* Whakapai Hauora and other similar trusts
* Early Intervention Trusts
* Facebook

1. **Questions for Discussion**

If there was a national network that represented the interests of families/whānau of children and adults with disabilities – what would it look like and do?

* Be 100% family driven
* Strengthen the voice of families/carers
* Look at what is already out there (ie. Carers Alliance)
* Strengthen family/carer networks
* Have clear membership guidelines
* Have core values that align with strengthening carers/families and the carers strategy

If a sector change process (like EGL) was to be expanded and sped up ….what needs to happen for carers/families/ whānau?

* Workforce development
* Clarity around what is in/what is out – lots of confusion
* Clarity around options (ie. direct funding) and process
* A lot more education and personal stories
* Need to have a transition period (opt in/opt out)
* Need to understand things like liability insurance (and the process)
* Safety net – not stuck with EGL
* Carers strategy embedded into practice
* Proactive – ensuring families have information prior to a new system change

***Action:***

1. Follow up regarding the Carers Strategy Reference Group meeting
2. Follow up regarding a possible male representative for the Advisory Group
3. Attach a copy of the Carers Strategy to the meeting notes and link (<https://www.msd.govt.nz/about-msd-and-our-work/work-programmes/policy-development/carers-strategy/>)
4. Follow up regarding having a member of the EGL leadership group attend the next meeting.
5. Organise for the Advisory Group members to provide a profile and photo for the Care Matters website

**Next Meeting Date:**

**Thursday June 29th in Palmerston North** (venue to be advised).