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| **Attendees**: Tina Lincoln (Care Matters), Christine Zander-Campbell (Parent to Parent), Dr Carey-Ann Morrison (Imagine Better), Shane Doull (Kitchen Table Whanganui), Wai Campbell (Kitchen Table Whanganui), Mark Benjamin (SAMS) by phone, and Rebecca Walton (Development Manager and Secretariat Support – Care Matters). |

**Apologies:** Katrina Fletcher (Carers NZ), Kellyanne Tong (NZDSN), Wendy Brenkley (Complex Care Network)

**General Update**

1. Update from Advisory Group members
2. Update from Mark Benjamin on System Transformation (by phone)
3. Update from Development Manager on Care Matters (ie. annual work plan, resource development, reporting and survey results, etc.)

*Summary of results and achievements*

The average number of people attending workshops over the previous 12-month contract period was 11. Participants reported 100% good, very good or excellent satisfaction at these events (please note most of the results were either very good or excellent). The feedback from the annual on-line survey reflected the results from the workshop feedback forms. There was no discernible difference between participant satisfaction between these two results.

Most of the workshop participants are typically European women who are between 30 - 59 years of age. Statistics from this period recorded 13% of participants as Māori. The average age of the person being cared for was 12.

All Kitchen Tables sessions have been completed and occurred in the following locations – Palmerston North, Levin, Oamaru, Timaru, Taupo and New Plymouth.

In analysing the last 12 month’s page views, the top pages viewed in relation to resources was those associated with the Time Line. Over the last six months this accounted for approximately 50% of all page views. These resources have proven extremely popular.

Care Matters was contracted to provide 10 resources over the 12-month period, these consist of:

* 4 podcasts (Parent to Parent)
* ‘Resilience’, ‘It's all about Relationship’, ‘EGL System Transformation’ and ‘Update and MidCentral Prototype’ resources
* Completion of Part Three ‘Adulthood’ and Part Four ‘Getting Older’ of the Time Line.

The top five *downloaded* resources were (1 being the highest number)

1. A window into IF/respite
2. Part Two: 7 - 18 (Time Line)
3. Home Ownership Guide
4. EGL Overview
5. Part 3: Adulthood (Time Line)

***New Contract & Resource Development 2018-19***

We have committed to providing the following resources:

*Parent to Parent*

4 x podcasts – EGL/Mana Whaikaha x2, Anxiety and Advocacy

ASD Booklet

DSS funding personal budget options (simplified version)

*SAMS*

Information for workshops/website – I CHOOSE, the Kaituhono/Connector role, Advocacy and EGL/System Transformation Update

Understanding the needs and expectations of families in the new era (e-leadership group)

Teaching the Teacher Aides (e-leadership group)

Sibling resource x2

Transition for Life resource (partnership with PVI)

**General Advisory Group Discussion**

1. ***‘Understanding the needs & expectations of families in the new era’***

What will families and providers need to think about?

*General Discussion*

* Providers need to understand that the funding sits with the disabled person and/or his or her family.
* No needs assessment.
* Complete shift in thinking for everyone (from the old system to the new).
* Importance of informing and equipping local families to be local leaders, particularly as System Transformation is rolled out.
* The disabled person and his or her family need to be clear about what they want. It is no longer about ‘units’ but about the life people want.
* Families need to be aware of what the funding can pay for – what’s in/out of scope? For example, paying for living expenses is outside of scope. Everything else is possible – if it is not illegal it’s up for discussion!
* Providers will need to be flexible and responsive to the needs of the disabled person and/or his or her family.
* Shift in power and control. Families can choose one service, multiple services, a ‘mainstream’ provider, or look to set up a purpose-built service.
* The disabled person/family do not have to use disability specific services – they can approach whoever they feel is best able to meet their needs.
* Providers need to be able to provide the service that the disabled person or family want.
* Understanding the downside ie. using multiple providers might increase the amount of administration (multiple invoices).
* You can make decisions about what accountability you want from the provider.
* Families and providers need to be clear about the difference between System Transformation and EGL principles.
* Families can’t assume providers and/or the workforce are aware of the EGL principles.
* Families can use the EGL principles as a lens to look at the service/s provided (ie. self-determination – are ddisabled people in control of their lives and how does the provider support this to happen?)
* There is some confusion about the Kaituhono/Connector role – families need to be clear about what they can/can’t do.
* Important for providers to understand the choices families have (ie. having someone else manage the funds through to managing the funding themselves).

*Critical thinking in exploring options*

Encourage critical thought – look at different pathways. What stage are you entering? What is it that you want? What supports and services are available? What questions do you need to ask? What understanding do you have of what is possible under the new system? What could this look like for my family member? What’s the right pathway for me and my family? Which pathway will get us closest to what we want?

*Upskilling the workforce*

Need to ensure workforce development validates lived experience. Balance between upskilling through formal qualifications and validating a family’s experience and knowledge. Need to ensure there is a way to include the family’s experience in training offered.

### [Capable NZ](https://capable.nz/about-us/capable-pathways/) through the Otago University enables you to have your knowledge and skills measured against an actual qualification, and you can use this to gain a qualification through your workplace.

*Setting up built for purpose services*

Need for families to have access to generic policies/procedures that can assist them when setting up a built for purpose service so that it makes it easier for families who are considering this as an option.

It would be great for families to be able to access policies that they can tailor to suit their own situation. Templates or information could easily be linked to websites like the Labour Department, the Charities Commission or Manawanui for employing staff. Rebecca will research what is already out there and discuss with Tina and Christine (who have expertise/experience in this area).

1. ***Advocacy workshop resource***

There is a lot of material already written on supported decision making. Care Matters does have some information/links to this material on the website. Rebecca to check if there is information about where families can go for support if this process breaks down.

1. ***Transition – All of Life***

This is a joint project with PVI (Parents of Vision Impaired)

*Key Transition/milestones*

0-6 The Early Years

7-21 The Middle Years

21+ Adulthood

Getting Older

What are some of the similarities for different key transitions?

* to plan early
* similar planning processes ie. IP’s, IEP’s, Transition Planning and Personal Plans (post-school)
* good communication (the ability to negotiate and deal with conflict)
* relationship building (the need to have key people walk alongside the student and family during key transitions)
* vision and pathways
* increased stress/anxiety (everyone will experience this differently ie. child/parent)
* ensuring the families experience is validated

What are some of the differences a family might experience at different transitions?

* need for specific knowledge/information (ie. knowing how important the first ORS assessment is for determining supports and services while at school or that services are not integrated post school, etc.)
* expectations – these may differ between the student, family/whānau, and school etc.
* support – will differ depending on whether you are pre-school, at school or post school (there will be different supports, services, staff and providers involved)
* need to be well informed about how to navigate the different ‘systems’ (ie. education, WINZ, funding, post-school services, etc.).
* supports and services will differ in different regions – the best services are often those recommended by other families, so it’s good to keep connected.

Typical questions to think about at times of change (families could brain storm this for themselves at workshops…)

* what do I and/or my family member want?
* what support do we need?
* what are the likely changes/challenges?
* how can we ensure the right support is in place?
* who will help us achieve this?
* what will remain the same/change for my family member?
* what will my/their day look like?

What sorts of things make the process easier?

* being knowledgeable about the services and or ‘system’ they must navigate
* get clear on what you want/don’t want
* being pro-active and asking questions
* plan for meetings and get what you need
* interview the school where possible (it is acknowledged there may be limited choice or options for someone who lives in a small town or rurally)
* build key relationships – getting the right people involved
* build in strategies ‘to get rest’ and choose which battles to fight, etc.

What happens when it’s all set up – but it falls over?

* where do you go for support when things change?
* how to keep things moving forward?
* how do you move forward, so the next Transition is easier?
* strategies to deal with stress and ways to lessen the load.
* reflective practice – what did/did not work (ie. writing things down).

Need for **practical exercise/s** and stories of people doing things differently or successfully navigating various key transitions.

1. **Teaching the Teacher Aide’s**

* Teacher Aides are not always valued.
* Teacher Aides support the work of the teacher.
* Teacher Aides may not have had any training (this is the responsibility of the school).
* The staff who support your son or daughter need to have some core key principles/values.
* You can ask if you can be involved in the employment selection of the Teacher Aide who will work with your son or daughter (different schools will have different policies on this).
* You can ask to meet with the Principal/Board of Trustees. Find out what the schools priorities are and how they support students who need additional support with learning.
* It is useful for professionals to share information (which doesn’t always happen) so everyone who supports your son or daughter is on the same page.

1. ***Older parents – strategy***

At the next Care Matter’s Advisory Group meeting the members will discuss how Care Matters can best 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.

Often support during significant change is targeted at the adult disabled family member and not the parent. Parents with a much older disabled family member may not have been mainstreamed and may have had a very different experience to younger families. Rebecca is to discuss possible strategies with Christine and look at possible ideas to support this work for the period 1 September 2019 to 31st August 2020.

Tina has been contacted by a family member who is creating a resource called ‘what happens to me when I die’? Rebecca will follow this contact up.

**Action Points**

* Wai to pass on family/whānau contacts for Northland to Tina Lincoln.
* Rebecca to include information on Career Force and Te Pou on the website. Support workers can do training through Career Force - and it’s free.
* Rebecca to link the EGL principles pamphlet to website.
* Rebecca to contact Mark Benjamin about resources that may have already been produced that might be useful to families who are setting up purpose built services.
* Rebecca to check out the information and links on the Mental Health Foundation website.
* Rebecca to add to Care Matters Terms of Reference a clause about being able to replace Advisory Group members should members be unable to attend meetings on a continuous basis (ie. 2 – 3 times). Rebecca to discuss and align with SAMS board policy.
* Rebecca to check out how Carer Force peer reviews their training material.
* Rebecca to check links that support disabled persons and families through supported decision making.

**Next Meeting Date:**

**Monday the 5th of August 2019 in Palmerston North** (venue to be confirmed).