**Enabling Good Lives (EGL) – MidCentral Regional Leadership Group**

**DRAFT Record of the meeting held on the 4th July 2018**

**Palmerston North**

1. **Present:**
   * Representing persons with disabilities: Martin Sullivan, Antz Burgess, Rose Boddy, Rachael Burt (disabled persons representative), Pete Allen and Rachael Kenny (People First)
   * Representing families:, Zandra Vaccarino, Selwyn Bennett and Pip Brunn
   * Representing providers: Janice Gordon (last meeting as a member) Group, Marshall Te Tau (last meeting as a member), Maxine Dale (from 12.30pm – new member) and Fiona Parrent
   * Representing Mana Whenua: Wairemana Campbell (Mana Whenua),
   * Representing Pasifika: Pati Umaga and three Pasefika family representatives

In attendance

* + Sacha O’Dea (Transformation Team at the Ministry of Health) and Toni Atkinson (Manager, Disability Support Services, Ministry of Health)
  + Jen Wilson (Oranga Tamariki)
  + Mark Benjamin (Facilitator for the group) and Tina Lincoln (Co-facilitator)
  + Apologies:, Lovey Hodgekinson (Mana Whenua), Robyn Richardson (Mana Whenua), Gabrielle Scott (DHB), Janice Gray (ACC), Sandra Marshall (MoE) and Katie Brosnahan (MSD)

1. **Welcome, karakia and introductions**
2. **Current issues**

The group had a round of expressing whether there were issues they wished to discuss.

This included:

* The importance of actively honouring diversity. In particular, the importance of acknowledging the rainbow community and tangata whaikaha
* Developing a shared and agreed use of language. The definition of “lived experience of disability’ was raised. This was scheduled to be discussed later in the meeting.

1. **Presentation from ‘A Good Start in Life’ and the Ministry of Education**

The Leadership Group was joined by: Pamela Cohen, Georgina Muir, Josi Wilson and Jill Ford.

* A Good Start in Life is an across- ministries project, led by the Ministry of Education, that comes from the New Zealand Disability Action Plan
* There are several groups, that include disabled people, whanau and providers that have informed and guided this work
* A key focus was: ‘ what are the things that will make the greatest (positive) difference’

**Key findings from A Good Start in Life**

‘Knowledge comes from learning and wisdom comes from letting go of what you think you know’

* Parents had to become resourceful and skilled co-ordinators
* People are not looking for programmes – the biggest variable to quality and effectiveness is the relationships that are built
* There is not one way – everyone is unique
* ‘services’ can create competition or suspicion – or, can build partnerships
* There are often too many people (and organisations0 in peoples lives

Critical challenge is to build a shared understanding. This includes:

* Respect
* Relationship
* Recognise everyone has expertise
* Building on what works best in local communities
* ‘professionals’ learning to slow down (not be immediate fixers) and to be empathetic listeners
* ‘professionals’ don’t need to know everything

Primary skills

* Slowing down
* Active listening
* Respect different perspectives
* Challenge current ‘culture’ (continually reflecting)
* Being OK about acknowledging mistakes

The biggest support for families is informed supports

To be effective, a new way of working needs to be practiced at all levels of the “system”

Three important things include:

1. Underlying principles
2. Access to information and supports
3. Understanding about how to integrate various supports (get rid of silos)

**Ministry of Education**

1. A desire to improve the system
2. Appreciate clear links with the ‘prototype’ in midcentral
3. There is an increased budget for learning support
4. Wanting to build better connections and alignment with other ‘systems’

**Progress with the education funds “in-scope’ work**

* Exploring how to reduce fragmentation
* Looking at the contribution ‘education’ can make to the prototype
* Held three meetings with people from the disability community i.e. Disabled People Organisations (DPOs), National Enabling Good Lives Leadership Group and people from the midcentral Regional Leadership Group

**These meetings looked at:**

* Building a connection with each other
* Looking at the $600 million dollars’ worth of investment (what the Ministry of Education is funding)
* What could be considered for being transferred into “the prototype”
* The group identified 19 areas they would like transferred. Further initial discussions related to the potential transfer of five of these areas
* Papers from these meetings are currently with Ministers
* Potential focus areas in the MidCentral region – training with School Boards of Trustees, partnering with teacher training, joint planning, peer connections and ‘work experience’

**Members of the group emphasised:**

* More flexible and seamless support
* Increased choice and control for disabled peopleand whanau
* Individualised funding
* Transparency
* Early learning partnership
* A ‘whole-of-life’ approach (not a focus on a specific Ministry)
* People want more time to work through the issues

**Next step questions to the MidCentral Leadership Group**

1. What are most important things to consider – specific initiatives?
2. How can links with ‘A Good Start in Life’ be progressed?
3. **Presentation from Palmerston North City Council**

Ian Littleworth and Peter Grey joined the meeting

* The council is going through a change process – this has included setting a new strategy and goals
* There is a connected community strategy. This involves:
* A welcoming and inclusive community
* Community leadership
* Feeling safe and being safe
* The council is not just interested in economic growth – but, also social growth
* Peter Grey is the Community Liaison Team Leader. He has a background working in the disability sector
* The ‘prototype’ is a great opportunity to work together as there are many similar objectives
* Up for involvement is bringing about a significant mind-set change in the community
* Some of the immediate areas of connection involve: the 400 social housing resource, disability reference groups (that are involved in policy settings) and connection with an inclusive and multicultural approach
* The council is interested in working alongside the community

**Next step questions to the MidCentral Leadership Group**

How do we want to build the relationship with the council?

It was suggested that Palmerston North Council take the step of being the first City Council to formally adopt the Enabling Good Lives principles as a way of working with the disability community.

1. **Selecting members of the MidCentral Leadership Group for the Governance Group**

Note: all of the Core Group meetings, prior to the Leadership Group meeting, discussed the Governance Group Terms of Reference – in particular the purpose and importance of this role and the skills and attributes required.

There is scope for a total of six members from the Leadership Group – out of a total of nine spaces. Initially, there was a discussion around how to split the numbers of the group to ensure equity and diversity. Two options discussed were four disabled people, one family member and one provider – or, three disabled people, two family members and one provider. After considerable discussion, it was the consensus of the Leadership Group the composition would be:

* Three disabled people (with a focus on ‘observers’ being disabled people – including tangata whaikaha)
* Two family members (with one family member from the Pasefika community)
* One provider

It was also noted that each member would be connected with a mentor.

The people the group unanimously supported being suggested to the Ministers are:

* Martin Sullivan (Disabled people)
* Peter Allen (Disabled people and Manawhenua)
* Rachel Kenny (Disabled people)
* Zandra Vaccarino (Family)
* Rasela Fuauli (Family and Pasefika)
* Maxine Dale (Provider)

1. **People for recruitment panels**

There will be multiple job interviews on the 11th, 12th, 16th and 17th July

Leadership Group members available on the 11th and 12th July included: Martin, Maxine, Zandra and Peter (12th)

Wairemana maybe available on the 16th.

Fiona Parrent available for all dates

It was decided that Core Group members may be approached for involvement on panels for the 16th and 17th . Please email the names of any potential people who are available to the System Transformation team.

1. **Comments on the draft Funding Allocation Cabinet paper**

There were several suggested areas of clarification or change discussed

1. **Definition of “lived experience” of disability**

At this point, the definition in some documents is “disabled people or family members”. It was suggested a distinction is made between the perspectives of disabled people and their family or whanau. The group expressed various views on this. It was generally agreed:

* All perspectives are valid and valued
* It may be beneficial to avoid the term “lived experience” as it has been defined and simply state disabled people **and** family members (not “or”)
* The importance of disabled people being self-determining

1. **Evidence based decision-making and network building tools**

There was general agreement that people believed the questions/concepts, as written, need to be challenged. For example:

* Whose version of “evidence”
* What may be “credible” to one person may not be to another

It was agreed that concepts more consistent with and Enabling Good Lives approach are:

* Are the tools consistent with the Enabling Good Lives principles? There is caution that some “tools” may be commonly accessible/promoted but may not be fully aligned with the EGL principles
* It is the people using the tools that may determine how appropriate and effective the tools are. This potentially needs to be clearly stated on any resource materials/ web-based resource list.
* It is critical that the listing of any “tools” listed on a website is NOT considered an endorsement of the tool

Some of the tools suggested by the group include:

* Materials from Helen Saunderson
* The Enabling Good Lives toolbox
* How I make my decisions i.e. an Easy Read document produced by People First New Zealand.
* I plan it
* How’s it going
* Keeping safe – feeling safe
* Pathway (Ireland)
* Kapasa

1. **Advocacy options**

**Advocacy Options -**

* How should we categorise or group information?

- Supported Formal Decision Making

- I need Advocacy to???

* What are the existing advocacy options in MidCentral?
  + Citizen Advocacy
  + Brain Injury
  + Parent 2 Parent
  + DPA
  + Down Syndrome Association – (Training)
  + Manawatu Community Law
  + Manawatu Gay and Lesbian Rights Association Inc.
  + Disability providers – CCSDA – IHC – Some residential
  + PAT (Personal Advocacy Trust)
  + Yoss – (Youth One Stop Shop)
  + Pacifica for tomorrow
  + Pakatatau
  + Anglican Social Services
  + Methodist Social Services
  + Te Ora Nui
  + Dina Whatnell - MidCentral DHB Disability Advocate
  + Whakapau Waikawa
  + Te Tihi
  + Disability Support Service - Massey University
  + Te puna Hauora

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| **Action point**  The Leadership Group decided to individually email Sue Hobbs directly with lists of additional advocacy within their communities. Discussions identified that many of these contacts may require opportunities for development with ‘System Transformation’.  Email address for Sue Hobbs is [Sue\_Hobbs@moh.govt.nz](mailto:Sue_Hobbs@moh.govt.nz) |

1. **Other Up-dates and issues?**

**Disabled People Leaders Update.**

A forum was held recently and was attend by approximately 25 people. Information people wanted to know about included;

* What are the nuts and bolts?
* How is this going to work for me?

A casual get together is planned for the 24th July.

Focus on;

* Exploring the ‘Vision and Principles’ of EGL.
* To create space for people who want to share their experience so far, find a way forward, and improve the future.

**Family Core Group Update;**

A forum was held in Dannivirke for the Tararua region 3rd July 2018. This was attended by five people from Dannivirke, and five people from MidCentral RGL, family/whanau core group and Sacha O’Dea (System Transformation MOH lead), Mark Benjamin (Lead Facilitator MidCentral RGL), Tina Lincoln (Co-Facilitator MidCentral RGL).

Discussions included thinking about the resources within the ‘Tararua Community’ and to connect with resources including MidCentral Family/Whanau Core Group. A representative was appointed to attend future Family/Whanau core group meetings from Tararua.

The Family/Whanau core group will hold a ‘meet and greet’ meeting in Levin. Conversations included the possibility of a collaborative (disabled people family/whanau – providers) forum being developed. Ongoing discussions will continue and once a set date is confirmed information will be sent out to the community.

**Provider feedback to RGL;**

Stated it was generous, a privilege, an honour to be part of the RGL. Thank you to the RGL for having providers involved.

**Mana Whenua Update;**

Recent connections included local Hui’s run my CCSDA Karanga Maha. The local Hui’s were attended by approximately. 15 people who identify as Maori. Approximately 1/3 of people are under the age of 30 years. Mana Whenua support leadership – aspirational – what people want to do?

Question asked to RLG? Can a person from the Hui be a representative for Mana whenua RLG? No one was opposed to the idea and ongoing conversation space for future directions was agreed to.

**General Updates from individuals within the RGL;**

* Recent attendance of a ‘Care Matters’ workshop in Levin. Feedback included how a thinking environment resulted in some people who came not thinking that change was needed changed to think about ‘the possible’ with thinking about ‘what a good life could look like’. The ‘Dream’ was exciting to hear from some individuals.
* Future intention of the National Leadership Group and MIdCentral Leadership Group to connect again in the near future. Date to be confirmed.
* An official ‘Powhiri’ will occur before the official start date 1st October. Date to be confirmed.
* A request to MIdCentral Leadership Group and ‘the new system’ to focus on intentional proactive outreach for people who have no connections in their lives outside of their ‘service provider’ within MidCentral region.

1. **Final Thoughts from the day;**

Robust Exhausting Hard Yards

Trust Joy Maturity

Honest Powerful Overloaded

And True Interesting Positively shattered

Heart Work Pink Emotional

Fantastic Honest Moved

Safe

Karakia - Finished with a Waiata ‘Te Aroha’

Departed 4.15pm

NEXT MEETING

8th August 2018

10.30am – 4.30 pm

Venue: Coachman Hotel, 140 Fitzherbert Street, Palmerston North