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

**Confirmed record of the meeting held on the 8th November 2017 in**

**Palmerston North**

1. **Present:**
   * Representing persons with disabilities: Martin Sullivan, Pete Allen, Antz Burgess, Rose Boddy and Rachael Kenny (People First)
   * Representing families: Selwyn Bennett, Zandra Vaccarino and Pip Brunn
   * Representing providers: Carol Searle, Janice Gordon and Marshall Te Tau
   * Representing Mana Whenua:, Lovey Hodgekinson and Wairemana Campbell
   * Representing Pasifika: Pati Umaga and Lovely Vaipulu

In attendance

* + Virginia Wilton from the Transformation Team at the Ministry of Health and Zach (note taker)
  + Jen Wilson (Oranga Tamariki), Scott Ambridge (Enable), Gabrielle Scott (DHB) and Janice Gray (ACC)
  + Mark Benjamin (Facilitator for the group), Jade Farrar and Tina Lincoln (Co-facilitators)

Apologies: Robyn Richardson (Mana Whenua), Rachael Burt (disabled persons representative), Katie Brosnahan (MSD) and Julie Hook (Education)

1. **Welcome, karakia and introductions**

Lovely, Virginia and Zach were welcomed to the group

1. **Overview of Core Group discussions**
2. There was general disappointment and frustration expressed that the transformation team had not responded to the interest expressed by disabled people and families who offered to participate in various ‘working groups’. There were a number of people who had not received any response and/or ended up in a working group that was different from the group they had registered an interest in. It was generally believed that providing a response was basic courtesy and that not being responded to did not reflect a move towards building a trusting partnership.

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| **Action**   * Jade will speak to members of the transformation team, on the 9th November, to seek an urgent response and apology * Mark will request that the transformation team provide a breakdown of the numbers of disabled people, families, providers and officials on the “working groups” |

1. The disabled persons Core Group was asked how they wanted small group work, at the MidCentral Leadership Group, to happen. It was generally believed it was best if people self-selected the small group they wanted to participate in and that groups would likely be “mixed”
2. It was emphasised that this was an early stage of developing material in the ‘working group’ documents. Everything is up for comment and this is a fluid time of co-development (not commenting on a finished piece of work). There are several groups that are contributing to each “working group”

* The “working group” (disabled people, families, providers and officials)
* A “virtual testing” group (a wide and diverse network of people)
* The EGL National Leadership Group - to ensure that everything is consistent with the EGL principles and vision
* The co-design group - to make sure detailed work remains consistent with the initial high-level work
* The MidCentral Leadership Group - to make sure there is a local voice, leadership and oversight in the MidCentral Region

1. **Progress up-date from the disabled persons Core Group**

* There is a sense of optimism and enthusiasm at the growing numbers of people getting engaged
* A facebook page is being developed
* A budget for on-going work is being finalised
* Disappointment regarding the absence of a direct response to people who expressed an interest in being part of working groups – this is not “Mana Enhancing” or “Relationship Building”

Note: Virginia, from the transformation team, responded by describing that there were considerably more registrations of interest than anticipated, apologised for the current lack of response to some people and agreed that urgent action was required

1. **Progress up-date from the family Core Group**

* Communication timeframes were not ideal and an extra meeting was required.
* A facebook page has been developed with 80 people already connected – this seems like a positive way to reach people.
* Current material on the EGL Website could be adapted to be easier to access and understand for families
* The context and intent of documentation needs to be clear when it is sent out (with clear timeframes)
* Plain language is critical
* People valued the “role play” which increased clarity
* A budget is being finalised and will be sent to the transformation team

1. **Progress up-date from the provider Core Group**

* An up-to-date contact list of providers is available.
* There is nearly 90 on the mailing list
* Focus on building trusting networks
* Need for clarification on “administration support in kind”?
* Continuing to explore how to address staff and families better regarding system transformation
* Some staff are expressing concern related to their job security
* Some people will be visiting the EGL demonstration in the Waikato to gather their insights

1. **Progress up-date Māori rōpū**

* Empathy interviews - key insights were Māori issues can be an afterthought and add-on. Work is being done to ensure a Māori perspective (and approaches) are woven into the system transformation approach from the start
* There is a need for this work to be covered, supported and protected – kaitiakitanga. What is a good approach/structure for this is being considered
* Exploration of how Māori values intersect with the eight EGL principles
* The group shared a video made of the recent wānanga

A member of the group expressed frustration that they had things to offer – but, they had not been included. It was expressed that communication, inclusion and recognising people have offered to invest energy (and skill) is greatly valued and creating the right spaces for people to contribute is essential

1. **Progress up-date Mana Tangata Pasefika**

* There have been challenges connecting with disabled people and families in the Pasefika community
* Two groups have now been established – Horowhenua and Manawatu
* Over the last three months, work has been done to increase people awareness of the disability rights movement and emerging opportunities
* Current mainstream approaches by officials and providers have not always achieved connection and clarity – people are disconnected. It is good to invest in approaches that work for pasefika
* More time required to reach the disabled people themselves and offer them support/information.
* Different people, interested in this work, may attend MidCentral Leadership Group meetings to get a feel for the best way to participate and contribute to the leadership of system transformation

1. **General discussion**

There are two time zones – the disability time zone and the ministries time zone. It is important this is recognised and that people and networks have the time to process information and different groups may require different pathways and timeframes to engage and participate. One size does not fit all – we need approaches that recognise the principle of equity.

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The leadership group divided into four smaller groups to discuss the papers from the “working groups” and provide feedback.

1. **Information tool, pathways and processes**

* Plain language is critical.
* Multiple ways for orientations development (video, face to face, social media etc), flexible access to information, multiple languages.
* Proactively engaging and welcoming.
* Paying attention to ensure people have been connected (and stay connected).
* Professionals (e.g. social workers, general practitioners) need to be empowered and upskilled with more information.
* Transparency
* Build from the ground up – by the people FOR the people it’s designed for.
* Immediate responses and consistency are imperative.
* Finding the right person to connect with people – a diverse range of Tūhono/EGL Connectors.
* Core values must be at the heart of all discussion, must be person directed/centred
* The system to fit people, not the other way around.
* Building trust and confidence is critical.
* The idea of “tandem” connectors floated so that people don’t have to start from scratch if they need to change connectors
* One person to connect with
* Face-to-face is essential

1. **EGL Team and System Capability Working group**Should funding decisions and funding allocation be separate from the Tūhono/EGL Connector functions

* Group one. If the connector has funding responsibilities this may impact on discussion around aspirations and whole of life/community focus. Therefore, prefer separation - but, there is still a need for immediate and direct access to some funds
* Second group agrees; for example, an “empowering” immediate fund compared to a more long-term fund. Some families may not even want a connector per se.
* Third group felt that the connectors do need some authority and power …. agreed with separate roles. Connectors would ideally support the family through the funding process, and should be independent. People should not need to repeat discussions.
* Fourth group expressed concerned about potential for connectors eventually assuming a “gatekeeper” role - therefore, advocated for separate roles.
* Tūhono/EGL Connector as the “north star” or champion of individuals and families
* Important forTūhono/EGL Connector to have no vested interest e.g. funding allocation or service provision

1. **System Responsiveness Working Group**

If something is not working – what/who do people need to connect with?

* External / independent
* Reframe as a ‘resolution’ or restoration process
* Not able to “pass the buck”
* Acting early important …. not a slow and reactive process
* Timely responses with transparency.
* There needs to be follow up and conversations around liability (particularly related to employment situations).
* Direct panel has been good, but this panel must have the authority to actually make changes.
* Multiple processes would be good.
* Change language - the complaints procedure needs to be focused on restoration and moving forwards. Solution-focussed model is better than a complaints-focussed model.
* Need to empower the people who are afraid to/don’t want to complain
* Peer-to-peer support should be encouraged to support complaints, as conversations can be difficult for many to have.
* Duty of care needs to be addressed.
* A concern floated about the balance between resources being used on independent panels vs. resources being directly allocated to those in need.
* Does every “complaint” need to go through a panel, or should there be more ability to refer people to the best resolution / learning process. Distinction between systems issues and people’s issues.
* Complaints not a primary solution – focus on capacity building, education, learning, development
* Replace the Health and Disability Commission

1. **Tūhono/EGL Connector working group**

What should the Tūhono/EGL Connector NOT do in regards to their roles?

* Disempower, discriminate or judge
* No personal gain
* Not connected to any potential provider
* Influence or manipulate
* The needs of the disabled person must ALWAYS come first over the wants of the family
* there needs to be a delicate balance struck by the connector between professionalism and friendliness
* Connect, but do not cross boundaries
* take on responsibilities they are not equipped to handle/not supported to help
* Care not cure
* Confuse or impose views e.g. mindful of the terminology between independence and interdependence.
* Connectors must support families to support minors in their growth towards independence themselves
* Be isolated – peer supervision and support

1. **Information Front End**

* Identify key leaders (and use them)
* Outreach does not necessarily have to be an independent role if it can be integrated into existing structures. Church groups, Red Cross and MSD floated as places to get the principles of EGL more widespread.
* A public education program using media is imperative.
* A personal letter highlighting ways to connect with more information, written in a way/language they can understand.
* Point of contact: Information needs to be made available for immediate needs.
* Federated Farmers an idea to reach those in need in rural areas. Educating isolated communities a priority.
* Creating and allowing time for thoughts and discussions around these issues rather than dictating responses.
* How can communication be adjusted so that it’s more consistent and accessible and comfortable for those who need it, yet retain the information within (plain language with the concepts and content relevant to the group).
* Consistent information and strategy.
* Some communities may need more resource than others e.g. Refugee and migrant, Pasefika + Rainbow community/LGBTQ+

1. **What does good crisis response look like?**

* Connect with someone who knows (won’t just pass you on)
* being believed and trusting
* Inform and expand existing universal crisis response approaches
* Someone who has the time and skills for crisis management, specifically checking in and talking to those in need
* A telephone setup is great, but one person can’t know every situations solution. Youthline for instance connect many people to other services while simultaneously staying connected on the line. 24/7 service recommended
* Quick response times needed
* Healthline as a more universal service could be more expanded
* Crisis lines are one thing, but responding to the crises themselves in a timely fashion is actually the priority

**12. Concluding word**

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| Unity | Accountability | Busy |
| Clarification | So so | Energising |
| Awareness | Learning x2 | Engaging |
| Enlightening | Information | Team building |
| Movement | Improvement | Developing |
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**13. The meeting closed with karakia at 4.05pm**

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| **Next meeting at 12.30pm – 4.00 pm on the 13th December 2017**. |