**Enabling Good Lives “Feedback Loop 2” Report**

**EGL Christchurch Demonstration**

**September 2015**

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**General Feedback Themes**

This is the second feedback loop conducted regarding what practices and processes are making positive change for those involved with Enabling Good Lives (EGL) and what areas need improvement and further development.

Interviews were conducted with 28 participants. A format of eight open ended questions were used and responses were collated. (Appendix 1)

In general, Enabling Good Lives continues to be seen as a positive initiative for providing individualised support. Three key themes were identified throughout the feedback process. These were:

* **Being in control & enabled to make own decisions**
* **Having access to a personal budget**
* **Navigation support**

A number of challenges and corresponding suggestions for improvements were also identified. They are, in brief:

|  |  |
| --- | --- |
| **Challenges** | **Suggestions** |
| Funding, budgeting, and information issues | * Provide clear Information to all involved earlier (schools, families, providers, agencies)
* Provide on-going training as support in family forums and other training events
* Provide easy to understand reference materials
* Simplify processes – especially paperwork
 |
| Staffing issues (connected to budgeting in some areas) | * Develop shared recruiting and training systems
* Development of staff management options
* Further explore hiring of family members as staff
 |
| Navigation | * Enable longer timeframes for navigation support
* Develop regular timeframes for reviews and ‘checking in”
* Explore other options for more choice within navigator pool – e.g. families as navigators, more choice in initial stages
 |

**Background and Aims**

This is the second ‘feedback loop’ conducted about the Christchurch Enabling Good Lives (EGL) Demonstration. The first ‘feedback loop’ was completed in November 2014 by Standards and Monitoring Services (SAMS) who also funded it

EGL commissioned Standards and Monitoring Services (SAMS) to undertake this second ‘feedback loop’ in order to build on the first one and to gather feedback about **what aspects** of Enabling Good Lives practices have **been of most value** to participants and families and **how these have been of value.** This will assist in determining the best way forward post demonstration.

**Method**

28 Interviews were conducted with participants of EGL. A combination of face-to-face interviews, telephone interviews and questionnaires were used to gather the information. Participants from the first ‘feedback loop’ were given the option to contribute to this second round and 15 participants took up this option. The remaining were randomly selected.

A team of three people, led by Rebekah McCullough were responsible for the interviewing. The other interviewers were Linda Leishman and Ruth Jones. They also reviewed the findings from this feedback loop. Both Ruth and Linda have a close connection with EGL and so methods were found to ensure they didn’t interview people who they had had an association with in this regard in order to avoid any potential conflict of interest. Rebekah McCullough conducted the analysis and wrote the report.

The graphs in the first section represent actual demographic information about participants. Pie charts were used in the analysis of the questions to illustrate the key themes from the participants’ responses.

**Statistical Information regarding Participants**

**Age range**

The age range of the individuals involved was from 18 years to 23 years with the exception of one adult in his 40s.

Family members were involved in 26 of the 28 interviews.

**Disabilities as identified by individuals and/or their families**

8 individuals identified as having more than one type of disability.

**Ethnicity**

**School Leavers or Opt In**

6 individuals were in the “opt in” category and the remaining 22 were school leavers.

**Analysis of Feedback**

**Question 1: What is the most significant change as a result of your involvement with EGL?**

***“I felt excitement about the future and the possibilities she could have.”***

**Choice and Independence** was reported as the most significant change for many of the participants. This represented a number of key points:

* Ability to be ‘in control’
* Ability to make own decisions
* Opportunities to explore options “outside of the box”
* Flexibility to do a range of activities at home and in the community
* Being independent

This was followed by approximately one third of the participants reporting that having access to their own **personal budget** had been a significant change and very much linked to making choices and being independent. Feedback included the following comments:

* Choosing how and what I spend my funds on
* Being able to employ my own staff
* Getting appropriate support

The process of **navigation** was the third most reported change. The most frequent comment was the development of a positive relationship with the navigator to assist and support the participant throughout the EGL process.

A range of varied responses make up the rest of the information and included feedback such as meeting other families and being in better health as a result of having individualised programmes (as opposed to being in day services).

**Question 2. What contributed to these changes?**

***“My navigator helped me change my thinking and look at possibilities not problems.”***

As shown on this chart, over half of the feedback related significant changes to having a **navigator.** The interviewers asked for specific examples of **how** the navigators contributed and the key following responses included:

* Developed a good relationship with participant and family/whanau
* Helped find interesting things to do rather than the standard expectations
* Helped participants become more confident and assertive
* Provided good support for planning
* Provided good support for challenges
* Provided good information and connections to make informed choices
* Guided and listened
* Assisted with developing and actioning a plan

Access to a **personal budget** was the second most articulated response. Again, the opportunity to use funds to support the individual how they wish to be supported was crucial. This included support to do a wide range of activities as well as hiring own staff.

Sessions for families to meet and training sessions were also seen as helpful.

Feedback regarding EGL not being helpful was related to the participant making changes for themselves not through EGL.

**Question 3. What aspect of EGL is of most value to you?**

***“EGL helps you help yourself.”***

The three key themes are repeated in the responses for this question:

* Access to personal budget
* Navigation
* Choice and decision making

Having a personal budget was identified as being of value primarily for what was called “flexible funding” by many respondents. This in turn, was seen as giving more options for making choices that were meaningful and relevant to the individual. Key to this was the process of navigation. Good navigation was identified as an integral part of the EGL approach.

**Question 4. What are the biggest challenges for you?**

 ***“While I am excited by what IF & EGL budget can bring, I feel daunted about having to learn so much more.”***

This question elicited the biggest range of themes, with the most significant challenges identified as **funding and budget issues**. In particular, responses included:

* concern about the amount of paperwork, various administrative systems and learning how to manage these
* time consuming nature of administration and budgeting
* budget issues around paying staff (whether to manage on own or use MIC)
* more clarity about what funding can and cannot be used for
* realistic funding for being out in the ‘community’ – taxis, admittance fees, membership fees, etc.
* transportation costs

Specific comments related to **staffing issues** were consistently reported as one of the dilemmas with the EGL approach. While on one hand the opportunity to hire one’s own staff is very much a positive aspect, the processes in recruiting good staff, training them and keeping them is often reported to be very time consuming and challenging.

The **timeframe for involvement with navigators** was also another area of feedback that participants felt was lacking. Most of this feedback stated that the initial planning was very good, relationships were built but then there was little or no follow up once a plan had been developed. This was not necessarily seen as the fault of the navigator, but rather the process, which many felt focused on the initial set up only.

Interwoven in this, is the **motivation** of individuals and participants. There was some feedback that the individual was difficult for family to motivate and more support from navigation would be appreciated. As well, there continues to be some concern regarding the **expectations of those in the community**. In particular, feedback was given about members of the community having lower expectations and the on-going difficulties in developing relationships outside of family and disability related support networks. This segways into the feedback related to the **expectations and pressures of family/whanau and natural supports.** This feedback centred around assumptions that family members would “pick up the slack” and always be available.

**Question 5. What are your suggestions for improvement of EGL process?**

***“I felt the navigator was great but she was cut off in the middle of our work. Because this is a demonstration I feel it is important that the navigator can have a catch up every few weeks without me having to initiate.”***

While a small number of respondents identified the **EGL as a good process** with no need to change, the majority of those interviewed offered a number of very helpful and constructive suggestions for improvement of EGL.

**Clearer information** **about funding, budgeting and pathways for negotiating the EGL process** featured as the most prevalent suggestion for improvement. Some of the suggestions for improving this area included:

* Start informing families much earlier about EGL
* Ensure that schools are informed and working with EGL staff to provide accurate information and good options
* Regular updates via email, post and navigators
* Regular meetings, trainings and forums at a range of times/places
* Simplification of financial processes
* On-going and relevant training on budgeting and planning
* Easy to use reference materials – especially for what funds can and cannot be used for
* A simpler system developed for monitoring and managing budget
* A drop-in centre for assistance and help
* Budget reviews need to be simplified with strict timeframes for LifeLinks and MIC.

A key suggestion regarding **navigators** was that there needed to be **longer timeframes for being supported by navigators and more on-going contact.** Participants were generally very positive about their interactions, relationships and support from their navigators. Even those who reported they were ‘having a good life’ stated that checking back from time to time would be welcomed. Others felt that getting established needed more time as this was all new territory for them.

Other suggestions regarding **navigation** included:

* Clearer timeframes about planning and how to monitor the plan
* More choices in navigators at the beginning
* Using successful EGL families as navigators – matching an experienced family with a new family
* Cloning the good navigators!

Suggestions regarding **staffing** **issues** included:

* Partnering with other/larger organisations for generic staff training
* Interviewing and choosing staff but having someone else to manage them
* Promoting payment of family members
* Sharing ideas about recruitment, hiring & training in regular family forums
* Development of ‘circles of support’ for more depth and looking into the future

**Question 6. What do you believe should be in place for other participants?**

 ***“There are many hours of unpaid work involving rosters, timesheets, organising staff, training, communicating with staff, phone calls, texts, emails, meetings….we do it for love….but we shouldn’t be taken advantage of just because we are family.”***

The graph illustrates the key themes that are aligned with the suggested areas for improvement in the previous question.

Ensuring that there is **clear information and processes** for new families was seen as a priority. This was specifically tied to the issues regarding **financial** **planning and budgeting support**. Many of the respondents felt that they had to “learn as they went” and this impacted on both their time, stress levels and decision-making. While it was reported that they had learned a lot, the emphasis on making it easier and less stressful for upcoming EGL families was important. Interwoven in this was the request for **more time with navigators.** The current navigation process is seen by many as having emphasis on the ‘starting up’ period but with little or no review or checking in once a plan has been developed. Participants reported that negotiating, budgeting, planning and trying to find out ‘what’s out there’ could be overwhelming. The support and guidance of navigators was seen as needing to be able to be for a longer timeframe and/or a negotiated timeframe of regular reviews.

**Question 7. Any other issues that impact on you and your family for having a good life?**

***“We need to teach our young people to adapt to curve balls and be problem solvers.”***

As the quote above, states, a number of individuals mentioned a positive sense of developing **resiliency** and determination to have a good life.

Nearly a quarter of those interviewed identified that they were **having a good life now**. This group also were generally satisfied with their navigator and their funding package.

There most significant impact reported was concern regarding **residential** **issues.** Issues identified included:

* funding for respite care
* funding for flatting
* moving into a residential care provider
* assistance with finding suitable housing

**Clear expectations** was another significant impact that is an on-going theme in this report. Comment was made by several individuals that the process was good but those involved, particularly schools and the families themselves, did not often seem to be sure of what was expected of them or others involve

**Question 8. Any other comments?**

 ***Thanks for the time and effort that has gone in to making EGL happen – long may it continue. Anything that helps us support our person to ‘have a good life’ is a good thing!***

**Areas for further development and consideration**

1. **Continued development of financial planning and budgeting systems**

This area of development is an on-going recommendation from the first feedback loop. While some participants report that this aspect has gotten easier, it is still reported as time-consuming and stressful.

It is clear that having access to a personal budget and more flexible funding options is one of the best aspects of the EGL approach. However, participants report that while this enables them to enact many of their own choices (hiring own staff, participating in chosen activities, etc.), it requires a range of skills that many feel they do not have or need further support to master. For an approach, like EGL to be accessible and easy to use for individuals and their families financial planning and budgeting needs to be simplified and adequate support systems developed to sustain this.

**Suggestions include:**

* Continued development and provision of clear Information to all involved earlier (schools, families, providers, agencies)
* Continued development of easy to understand EGL pathways and processes
* Further development of on-going training and support in a range of ways - family forums, one-to-one support, families supporting other families, specific training events, website training and on-line reference materials
* Provision of easy to understand reference materials
* Simplification of processes – especially administration and paperwork
1. **Continued development for employment, training and management of staff**

Hiring one’s own staff is another very positive aspect of the EGL approach. The recruitment, hiring and training of support staff continues to be an important area for development. Some good initiatives have been developed such as setting up shared staffing networks on the Internet. However, families report that this can also be a difficult area where they have had minimal experience.

**Suggestions include:**

* Development of shared recruiting and training systems – partnering with other organisations, supporting disabled people to develop training packages relevant to their support needs, group forums for idea sharing and problem solving
* Development of staff management options – e.g. participant may be involved in recruitment but an independent person is responsible for day to day management, payment, etc.
* Further explore hiring of family members as staff
1. **Continued development of navigation process**

The navigation role has been highly valued and appreciated as a way of being supported and guided through this new approach towards self-determination. Critical to this role is the development of good relationships between the disabled person, their families and their communities. Most families report that their navigators are helpful, respectful and knowledgeable. However, the main concern was in the amount of time that navigators are able to spend with families. It is recognised that the navigation role is to support disabled people and their supporters to become able to negotiate their own ‘good lives’ over time. However, this is seen as “new territory” for many and the need for more on-going support was stated time and again in this feedback loop.

**Suggestions include:**

* Enable longer timeframes for navigation support – more flexibility in terms of timeframes for support and checking in
* Develop regular timeframes for reviews – this is an opportunity to continue to monitor and gather information once the initial plan has been developed. This would enable an internal evaluation process which could provide on-going feedback about the EGL process
* Explore other options for more choice within navigator pool – e.g. families as navigators, more choice in initial stages
1. **Continued development of community involvement and use of natural supports**

Within this feedback loop there were reports regarding the use of natural supports, family as natural supports and connections within the community.

Anecdotal reports indicate that there is more variety in the range and types of activities that participants are involved with as compared to the last feedback loop. There were some reports of very positive interactions and connections between individuals and their local interest groups and communities.

However, the process of becoming truly included into one’s own communities of interest and local communities, in ways that lead to meaningful and sustaining relationships is an on-going journey. Several respondents noted that the “community” has low expectations of disabled people and this continues to be a barrier. Others stated that there was a reliance and even expectation that family members would ‘fill in the gaps’ while in other situations family members were not seen as appropriate support, even if that was the disabled person’s choice.

Continued exploration of these issues are an important process of the developing nature of learning how to truly include one another.

1. **Exploration of Residential issues and EGL approach**

Concern regarding a range of issues in the area of where one lives was commented on in this feedback loop. In particular, it was noted that there is some confusion about how funding can be used to support individuals who may wish to move out of home or explore a range of living options.

**Suggestions include:**

* Provision of forums for discussion about living options
* Provision of forums for discussion regarding respite support
* Provision of forums for planning for the future

**EGL Principles and Current Recommendations**

|  |  |
| --- | --- |
| **Principle** | **Current Feedback Recommendations** |
| **Self-Determination** Disabled People are in control of their lives. | This aspect of EGL continues to be a key positive of this approach and one that must continue to be developed  |
| **Beginning early** Invest early in families and whānau to support them; to be aspirational for their disabled child; to build community and natural supports; and to support disabled children to become independent, rather than waiting for a crisis before support is available. | The feedback continues to be clear that beginning early is imperative. The need for accurate information about processes and pathways needs to be started long before transition from school begins.  |
| **Person-centered**Disabled people have supports that are tailored to their individual needs and goals, and that take a whole life approach rather than being split across programmes. | The feedback clearly shows that being able to identify and pursue activities, interests and relationships that are important to the individual is key to the success of the EGL approach and is an area for continued development. |
| **Ordinary life outcomes**Disabled people are supported to live an everyday life in everyday places; and are regarded as citizens with opportunities for learning, employment, having a home and family, and social participation - like others at similar stages of life. | Anecdotal reports indicate that there appears to be an increase in the range and types of activities that individuals are involved with. |
| **Mainstream first**Disabled people are supported to access mainstream services before specialist disability services. | The recommendations from this feedback state that continued development of true inclusion into one’s communities of interest and local communities needs to continue. |
| **Mana enhancing**The abilities and contributions of disabled people and their families are recognised and respected. | While this is an on-going process, the statistics regarding those involved with EGL may be an opportunity to look at how this approach is promoted to Maori, Pacific people and other ethnicities. |
| **Easy to use**Disabled people have supports that are simple to use and flexible. | This feedback loop clearly shows this is one of the most vital and urgent areas for continued development and improvement. |
| **Relationship building**Supports build and strengthen relationships between disabled people, their whānau and community.  | This feedback loop identified the roles of family, natural supports and development of relationships within local community as areas for continued development. |

**Conclusion**

As this is a demonstration project, it is critical to continue to identify areas for improvement and development. The process of gathering information by hearing from disabled people and their families is fundamental to the on-going development of Enabling Good Lives, especially as it moves towards ‘post-demonstration.’

As well, this feedback loop, as with the previous one, clearly identifies that the Enabling Good Lives process is something very worthwhile and meaningful to those involved and must be further developed.

Once again, we acknowledge and thank all of those who shared with us so honestly and openly for this feedback loop

**Feedback Loop 2 Questions for Enabling Good Lives**

The aim of this questionnaire is to gather feedback about what aspects of Enabling Good Lives practices have been of most value to you and how these have been of value. This will assist in determining the best way forward post demonstration. Your responses will all be confidential. A final report regarding this feedback will be provided to all participants. I appreciate the time you are taking to do this questionnaire. Please feel free to expand the space to answer these questions. We would appreciate as much specific information as possible. Thank you!

**Statistical Information:**

**Name:**

**Age:**

**School Leaver or Opt In**

**Type of disability:**

**Ethnicity:**

**Person supporting me with these questions:**

1. **What is the most significant change as a result of your involvement with EGL?**
2. **What contributed to these changes?**
3. **What aspect of EGL is of most value to you?**
4. **What are the biggest challenges for you?**
5. **What are your suggestions for improvement of EGL process?**
6. **What do you believe should be in place for other participants?**
7. **Any other issues that impact on you and your family for having a good life?**
8. **Any other comments?**