**Enabling Good Lives in**

**Canterbury**

**June 2012**

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**A Report Collated by Gordon Boxall and Mark Benjamin for The “Steering Group” for the Enabling Good**

**Lives Canterbury Project**

**Foreword from the Compilers**

Having had the privilege of working with many diverse and enthusiastic groups during this project, we felt it important to share our reflections. Our intent is they might resonate with people and influence how the work may be most effectively taken forward.

We accept the Plan itself is important but not as important as the underlying principles. We believe the country needs to adopt these wholeheartedly if disabled persons are going to be equal citizens who get the opportunities to live lifestyles that the majority of New Zealanders enjoy.

The approach to developing the Plan has been evaluative, communicating with and listening to what disabled persons, family and providers say is needed. The next step, the implementation phase, should consider the plethora of evidence and resources that are available on the systems and practices that work well.

We believe that our findings are consistent with empirical studies conducted previously in New Zealand and overseas, particularly those that have focused on how the system needs to change. There is some concern that *Enabling Good Lives* will end up being a report which doesn’t lead to action. We call on those who hold sway to be brave in building on the relationships and trust that has emerged through this process.

This is a time for strong leadership both from disabled persons and family/whanau. We believe now is the time for tangible direction from people who believe disabled persons deserve the rights and opportunities that similar words, in multiple reports, over many years have described but not fully produced. We urge that Ministry staff engaged in this work are also supported to know how the work they do, regardless of role, contribute to disabled persons experiencing a good life.

The approach outlined in the Plan is not a new phenomenon. It has been trialled and tested in much bigger systems than New Zealand, including for example in the United States, Canada, Australia and the United Kingdom. None are perfect and all face challenges. However, they all are continuing down a path of expanding the commitment to personalised approaches for disabled persons by ensuring that supports are flexible and responsive to people’s aspirations which, in turn, are driving the market responses.

Whilst undertaking this work we came across many examples of good practice and innovation. The impression is that these have to be done ‘under the radar’. Many people felt that the system currently demands and measures the wrong things.

These examples of emerging good practice can assist us to know what does help disabled persons to get a good life and build from there. We therefore want to acknowledge the people and organisations that are brave enough to keep innovating and pushing the boundaries.

We have also seen the innovation of both Ministries. The resonance of *Enabling Good Lives* to for example, the New *Model for Supporting Disabled People*, *Going Places*, and *Pathways to Inclusion* are clear. We recommend that, in the future, these types of approaches and models should be part of the mainstream and not, as perceived by some, out at the margins. They also need to be complementary to each other. Of course, this project couldn’t have begun without people in authority recognising this and we believe that an effective change management programme with a mandate to encompass all relevant Government Ministries is critical to success.

Everyone recognises the challenges that we face with the economic situation and the scale of change needed. However, it was strongly felt that the current resources allocated could be more effectively utilised. This would be the case if the system supported the ability to be more flexible whilst ensuring sufficient safeguards are in place for vulnerable people and for where there are limited funds.

We recognise our influence in this report whilst trying to ensure that our approach, style and content have been true to the intentions of getting key stakeholders across all parts of the system to have freedom to voice their view. The Plan isn’t intended as a Blueprint or finished article. It is more a framework from which to create system redesign that would lead to more disabled people getting better lives for the money expended.

We also feel that it needs to have cross-party political support. It is too important and will take far too long to implement for it to be one ideology or another. Whilst, inevitably, there will be different emphasis and style, *Enabling Good Lives* needs to transcend Party Politics. Our ideal would be to have a Cross-Party and Cross-Ministry call to action that embraced the principles and is committed to the vision. If the Plan (or something that emerges from it) is not embraced by all Ministries then it will not succeed. We believe it is as simple and, of course as complicated, as that.

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**Executive Summary**

*Enabling Good Lives*, Canterbury sets out to produce a Plan that describes the “first steps in developing more individualised, facilitation-based supports for disabled people in Canterbury”. This include how to combine funding streams, from two government departments, so disabled persons and their families/whanau have more choice and control over what they do during the day.

The method for doing this was to design a process that was led by disabled persons and their families along with significant input from public servants and provider organisations. A number of parallel groups representing, local, national and government interests were established to direct and oversee the project. In addition, feedback from a range of local stakeholder group meetings ensured the outcomes were truly ‘ground up’ rather than ‘top down’.

Initially, there was scepticism but also a sense that this opportunity was too important to let that get in the way. Once engaged, people and organisations were fully committed to the process.

It was soon clear, as with the original *Enabling Good Lives* Report, theCanterbury Plan would need to describe a full systems change if it was to be true to the interests of disabled persons. This is a key feature as it is currently believed the way government organises its responsibilities and functions does not fit well with the way people live their lives.

In contrast, the principles upon which government has been designing new ways of working, based on the United Nations Convention and NZ Disability Strategy, were said to provide a much better fit for people. These approaches, which propose that disabled people (with the support of their families/whanau) have more choice and control over their lives, are consistent with a trend across many developed Countries. This is combined with a commitment to ensure disabled people can access the ‘mainstream’ rather than be confined to segregated settings.

The Plan contains a call to action for government to break down the policy and funding silos that are widely reported to confuse, complicate and sometimes prevent disabled people and their families from obtaining information and supports needed to live a good life.

The Plan proposes a way to include disabled people and their families/whanau directly both in the development of cross-government policies and also in the way these are translated into practice locally. This ensures an opportunity to work more collaboratively and involves a real shift of power.

The Plan proposes that the current system is transformed with a step-by-step description of how this could be achieved. Essentially, it details how to move from concentrating on what people can’t do (and matching deficits/needs to available services) to focussing on what people can and aspire to do (and assisting them to navigate their way to get a good life). Where practicable, this would be within mainstream settings and with specialist support as needed.

It recognises that some services are ahead of the current system in terms of considering how services can be personalised. It notes there are examples of innovative good practice which need to be acknowledged and built upon.

This Plan considers it important to stage any changes carefully as organisations need time to adapt and adjust to a new system. It proposes a twin-track approach to achieve this. The first sets out to transform services, how they can self-review and be evaluated independently against *Enabling Good Lives*. This would identify what would help them to improve and assist them to develop an action plan for implementation which would then provide a reference point for monitoring positive change. The second approach is system transformation. This is proposed to be developed in parallel with service transformation. Clear steps detail how this could be achieved. The new system would first become operational for school leavers from January 2013 and then be introduced to everyone at a future date. At that point, all disabled persons and family/whanau will access supports through the new processes.

It is considered services will develop different pathways based on each disabled person’s preferences which would be a feature of the new system. The new system would also look to the mainstream supports and opportunities first.

The new system, based on *Enabling Good Lives*, will offer eligible people portable funding with which to purchase necessary things to support them to have a good life. It is proposed that there will be a need to build the capacity of disabled people and their families to help them to do this.

Independent Facilitation is seen to be a crucial feature of the new system as an ally of the disabled person and their family. It is therefore proposed for this role to be made available outside of the provider or funder arrangements. This will require further structural change in the system although the role is seen to be consistent with the Local Area Coordination approach.

The adoption of the *Enabling Good Lives* (Canterbury) Plan would integrate disability into all situations rather than leave it at the edge or outside altogether of mainstream planning. Disabled people, their families and many of the agencies involved in this process are ready to put in whatever hard works it takes to make this a success.

**Background**

The Ministries of Health (MoH) and Social Development (MSD) each have responsibilities to support disabled persons to access better opportunities to lead the sort of life that the general population of New Zealand enjoys. Historically the Ministries have often worked independently of each other. A number of attempts, over a long period of time, to integrate the funding has proved unsuccessful. However, the differences are now increasingly been seen to be anachronistic and make little or no sense to disabled persons, their families or even to the agencies working in the service system.

The publication of *Enabling Good Lives* underlined the complexity of this area which, it noted, is very difficult to detach from other aspects of life. These include education, employment, housing arrangements and transport, all of which have implications not just for each of these Ministries but also a number of others. The authors of the original report were asked by the Minister for Disability to consider what a system, to support disabled persons to have a good life, would look like if it started from scratch. The report concluded that it would look quite different from the system that is in place with an emphasis that disabled persons and their families should have much more influence in how supports were designed, chosen and paid for.

The timing of the publication coincided with a range of other strategies and initiatives within MoH that come under the term *New Model for Supporting Disabled People* that each seek to support disabled persons having more choice and control over their lives.

The Ministries response to *Enabling Good Lives* was to test what this might look like in one part of the Country. Canterbury was chosen as it already has to rethink how it provides such services due to the significant disruption caused by the earthquakes.

What follows is how that process was established and the journey it took in order to identify what was needed and how best to achieve that over a period of time.

**Introduction**

This report is based on input from a diverse range of local participants.

It is worthy of considerable note that common themes quickly emerged from the people who chose to become involved. Some active participants in the planning process identified this opportunity as being two decades in the making and welcomed the chance to participate in the design of service and systems change.

Members of the *Enabling Good Lives* Canterbury Steering Group expressed ambition to retain a sense of “ownership”. Their stated preference was to have an on-going governance role in the transformation process.

There was enthusiasm for change amongst many of the participants. There was recognition that some core elements being promoted had been a feature in some Ministry of Social Development funded vocational services for several years e.g. aspiration based planning and the role of a facilitator. It was also felt there was close alignment to the Ministry of Health’s New Model for Supporting Disabled People initiatives which endorse a shift in power to disabled people, focus attention on a personalised approach to planning and promote Local Area Coordination as a facilitator-based approach.

There was a strong desire that new initiatives be built on the solid foundation of previous achievements.

Participants in meetings and contributors to the consultation process have generally endorsed the *principles* based approach of the *Enabling Good Lives* Report believing it can be a way to obtain clarity, innovation and flexibility. This is particularly evident when it is compared against the current *compliance and procedures* based approach.

A consistent message received was that positive changes will require both ‘service’ and ‘system’ transformation. This necessitates that all initiatives, across a number of Ministries, are joined together under a common strategy.

The potential of a move towards an *aspiration based* approach to personal planning, with this being the central document to design and measure paid supports was welcomed as was the associated move away from the Needs Assessment and Service Co-ordination model. Participants said that unique and changing aspirations are to be expected and supports and services will therefore need to be continually adapting how they contribute to assisting people to build and maintain a good life.

Considerable value was afforded to the Independent Facilitator role if they were allied with disabled persons and families. Participants’ acknowledged this role has the real potential to assist individuals and families to extend their view of what is possible, strengthen personal networks, support individuals and families to navigate existing options and *dissolve* funding silos (from the perspective of individuals and families).

General support was given for the move to a facilitation based approach/model for all existing services. Concern focussed on whether externally imposed changes could erode existing valued services. Participants urged that changes be negotiated person by person, family by family and service by service. It was considered critical that the preferences, aspirations and informed choices of disabled persons and families would be given paramount importance. It follows that if people choose to continue their existing arrangements then that would be the outcome. Either way change would be incremental and transitioned towards a time when a new system could be introduced.

It was predicted that a move to a common principles base, common processes and a common outcomes measurement would mean that people would create different pathways. This would be a defining feature of future supports and services.

There was also strong support for good employment to be a primary focus of a disabled adult’s day as this so strongly represents citizenship and inclusion in New Zealand society.

It was recognised that there is a fine balance between services being secure in the knowledge that they will be viable and disabled people having ultimate choice about how they spend their day.

It was also noted that many services are financially vulnerable given a longstanding and ongoing requirement to do more with less and due to the different approaches and paperwork duplication under the current contracts with MoH and MSD.

This review did not attempt to quantify the wasted costs incurred by duplicating effort, or managing and measuring existing unsatisfactory arrangements within and between Ministries but it is clear that considerable energy and resources are expended before budgets get anywhere near assisting a disabled person to have a good life

It was also recognised that some existing service and systems approaches would require significant adaptation. It was accepted, by some, that there are current approaches no longer consistent with existing and emerging expectations and aspirations e.g. Needs Assessment, Certification and piecemeal sector planning.

It was endorsed that the Plan would be inclusive of all eligible people regardless of their level of disability or capacity. It was noted that some people would need more support to ensure their dreams can be realised but this should be an ambition of the Plan so that having a good life is realisable by all disabled citizens of New Zealand.

Recognition of, and adherence to, issues of cultural integrity was also considered to be crucial and the alignment with, for example Whānau Ora was observed. Along with ensuring inclusion in the consultation process of a range of stakeholders and taking into account both the Maori and Pasifika Disability strategies.

It became apparent to several groups that a natural place to begin to implement systems transformation was in the period of transition from school. There was general agreement that when changes have begun to become embedded then there would be a move to ensure the facilitator role starts as early as possible with families. The Plan unapologetically starts and ends with the disabled person. Having a good life is not about having government central to it, but government has an important role to set the conditions and resource communities in creative ways to ensure that they can accommodate all citizens in all activities. That must be the on-going ambition to transition towards that ideal. Anything less would undermine the NZ Disability Strategy and those who fought so hard to endorse the UN Convention on Human Rights. And there was a real optimism that it could be done. As one valued contributor to the steering group who was a delegate at the Convention put it *“If 150 + countries agreed to sign up to that, how hard can this be?”*

With so much of the infrastructure destroyed, Christchurch has to lead the way in ensuring its rebuild creates communities that are accessible for everyone. If looked at across all government institutions it will be seen not as a cost but as an investment not just to do the right thing, although that should not be lost, but to ensure people can be as independent and self-reliant as possible, contributors to society and active participants in their neighbourhoods. In short, it should be cost effective to do so.

The Plan cautions that sufficient time, care and resources need to be made available to ensure the next phase of development is robust, sustainable and consistent with the principles and intent of the *Enabling Good Lives* report.

**Key Messages**

* A very diverse group of people is included in the term “disabled persons”. This means different supports, services and approaches are required in order to achieve equity
* For disabled persons and family/whānau to experience real choice and control, complete system change is required
* System change must be across Ministries, ‘joined up’, strategic and consistent with the expectation and aspiration expressed by disabled persons and family/whānau
* *Enabling Good Lives* can provide the basis of a framework that weaves together all initiatives
* Disabled persons and family/whānau national networks have key roles in both National and Regional Governance of systems transformation (see diagram below)
* *Enabling Good Lives* (Canterbury) involves immediate change (i.e. service transformation 2012-2014) and medium term change (i.e. system transformation)
* A starting place for ‘system transformation” is when individuals transition from school
* When “system” transformation is completed all individuals and family/whānau will have self directed individualised funding – this may be used in multiple ways
* Many of the functions currently held with Needs Assessment and Service Co-ordination organisations (NASCs) need to be replaced by two separate functions in distinct organisations i.e. a simple assessment to determine and confirm funding levels and Independent Facilitation. The foundation document for designing supports, services and funding will be an aspirational personal plan
* All services will move towards an approach that makes it easier (towards ‘facilitation’ and away from ‘provision’) for disabled persons and families to create good lives for themselves in the community
* A primary focus for services is to assist disabled persons and families to access quality community based (generic) supports and services
* A primary focus for services that operate during the day (Monday to Friday), is to make it easier for disabled persons to participate in mainstream employment, education and other inclusive activities
* All initiatives are developed with the reasonable expectation they can improve supports and services i.e. do no harm

**Process for Developing the Canterbury Plan**

The Ministries of Health and Social Development commissioned Gordon Boxall and Mark Benjamin to design a plan that tested and applied the ‘clean sheet of paper’ *Enabling Good Lives* Report to the earthquake affected area of Canterbury. Notwithstanding the need to consider other related aspects to a person’s life, their focus was to make better use of existing resources currently deployed for day and community participation services.

Three working groups were established:

1. **National Network** - comprising representatives of key stakeholder groups
2. **Officials** – comprising key operational and policy managers from each Ministry
3. **Local Steering Group** – with nominated representatives from the National Network agencies plus identified local community leaders in the disability sector

Each of these groups met regularly through the process and one meeting was held with all groups together to test the degree of consensus and to ensure the approach was demonstrably open and participative. In addition, three facilitated stakeholder groups (disabled persons, families and service providers) each met on three occasions to share the Plan’s purpose and gain people’s insights and expertise about what it should contain.

A pro-forma was designed and widely circulated to offer individuals and organisations an additional way of contributing to the Plan.

A number of responses were made directly to individuals, organisations and representative bodies who required more information or updates for their members through the process.

The intention of the contributors to the Plan is that both the process used in compiling the Plan and the content of the Plan honour the principles contained in the *Enabling Good Lives* report. This is reflected in the following:

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| **Self determination - tino rangitiratanga** | Supports and services have the ability to tailor their development according to the expressed preference and aspiration of individuals/families as well as their service strengths and circumstances |
| **Whole of life** | Systems change must be comprehensive and strategic for disabled persons and families to experience a ‘whole of life’ focus |
| **Ordinary life outcomes** | Supports and services have a unified purpose i.e. enabling people to create better lives for themselves |
| **Mana enhancing** | Existing achievements and innovations within the sector are acknowledged and current networks are recognised |
| **Mainstream is the default** | All supports and services will seek to develop and affirm links with community options and positively influence “mainstream” providers to maximise choice for disabled persons and families |
| **Kotahitanga tatou – whānaungatanga** | Efforts are made to strengthen the voice of all stakeholders with a view to finding common ground and a unified way forward. The foundation for development is trusting relationships and face to face communication is promoted |
| **Manaakitanga - Community building** | It is recognised that positive system change requires open information sharing, collaborative approaches and shared effort |
| **Timatanga (beginning early)** | The contents of the Canterbury Plan are based on the ideas generated by local disabled persons, families and providers  The Plan suggests that systems and service change is first integrated when individuals are transitioning from school. The intent is for the Independent Facilitator to begin working with individuals and families as early as possible. This will require considerable work with a range of Ministries and providers |
| **Simplicity** | Proposed changes will be communicated in a clear manner and in multiple formats  A core premise of this Plan is that disabled persons and families will eventually experience a system based on one person, one plan, one set of principles, one set of general outcome measures and one monitoring/evaluation process that apply across all Ministries and paid supports/services  A primary expectation is that the Independent Facilitator will assist disabled persons and families to effectively navigate through existing options and create new opportunities  Individuals with complex and high needs will be included in all aspects of service and system redesign |
| **Flexibility** | This Plan recognises that a diverse range of approaches, supports and services are required. It is expected that disabled persons and families will make different choices when different options are available. |

1. There have been ten forums hosted in Canterbury, three meetings of the National Networks and multiple individual visits and discussions. Specific efforts have been made to ensure that representatives of Maori and Pacific interests and people with high support needs all have the ability to contribute their unique perspectives to this process

* **National Networks** i.e. disabled persons, national organisations, national family organisations and provider representative groups.

Purpose: respect, affirm and engage existing networks

* **Canterbury Steering Group** i.e. an equitable representation of local disabled persons, family/whānau and providers.

Purpose: To design a long term plan for the local implementation of ‘Enabling Good Lives’

* **Stakeholder forums** i.e. disabled persons, family/whānau and service provider forums.

Purpose: Use a parallel caucusing approach to enable direct in-depth discussion

1. **Stakeholder Forums**

completed a ‘blank page’ process of identifying broad stages and expectations related to transformation i.e. “what do you expect to see?”, “what would you like to see?” and “what would you love to see?” There have been common themes emerging

considered existing service and sector strengths, challenges and aspirations

discussed concerns, what would be considered to be a *bottom line* and what is perceived as an *ideal* outcome when changes have been made

The Enabling Good Lives Steering Group (Canterbury) has considered transition steps that will enable all existing services to move towards a individual/family customised “facilitation” based approach *and* a new support and service system where individuals and families craft supports and services to suit unique preferences, strengths and aspirations (i.e. external facilitator – navigator – guide)

The EGL Steering Group (Canterbury) believes it is highly desirable for these new initiatives to be transferrable beyond Canterbury.

**Enabling Good Lives - The Canterbury Plan**

**Vision**

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| **A society that highly values the lives of disabled people and continually enhances their full participation.** |

**General Purpose**

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| **To incrementally transition current services to a facilitation-based support model. The focus of facilitation-based support would be on enabling disabled people to do everyday things in everyday places in communities, rather than on provision of ‘special’ places or activities for disabled people. It would include support funding from across government agencies that would be individualised and flexible.** |

**Project Aim**

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| ***Enabling Good Lives* in Canterbury (Phase One) draft a plan with practical and realistic steps for disabled people, providers and government agencies that could be taken to transform day and vocational services for disabled people in line with the principles and values contained in Enabling Good Lives.** |

**Canterbury context**

It is recognised that a number of providers have already taken steps to offer services that are based around an individual and that are also linked to mainstream activities. This Plan sets out how this could be tested, accelerated and become the norm rather than the exception, but one person at a time.

Some people gained the opinion that *Enabling Good Lives* was suggesting all existing centres had to close. This generated strong feelings, particularly where people have high support needs, and distracted the process by sometimes, for example, taking time to address in stakeholder meetings.

The process adopted, encouraged different stakeholder groups to work independently to identify what they think needs to happen in order to ensure there is a pressure for all supports to offer ‘everyday things in everyday places’. This has identified some likely barriers to the aspirations of *Enabling Good Lives:*

* There is a lack of trust in the system for some people who are suspicious of a hidden agenda
* There is a fairly common view that this is about money and the need to make savings
* It is also thought (and perhaps feared) that the Ministries will impose what they want anyway
* The current system appears adversarial rather than collaborative

The above concerns manifest in a number of ways both in the Steering Group and in Stakeholder Meetings. It was felt that it has been helpful that the project staff are independent of the Ministries and able to reassure people and at least keep them engaged.

On the other hand, a number of people see that the process adopted to develop this plan is refreshing, recognising the role and status of key national bodies and their local representatives and is open and empowering. As such it offers perhaps a unique opportunity to co-develop solutions that work, are locally owned and can drive the change that is needed if *Enabling Good Lives* is to be implemented and become sustainable. There is consensus that if all parties want it to work then it will.

Being uniquely placed to have met and received feedback on each group, the compliers are pleased to report there is much more in common, than differences, and a genuine desire for progress.

**It was agreed by the Steering Group that further progress considers the following:**

* The need to keep the momentum going – it is perceived that in the past more energy has gone into planning (and theory) rather than implementation (and, particularly, follow through)
* Change occurs at a pace that enables clarity and learning
* There is on-going oversight, monitoring and governance by all key local stakeholder groups i.e. disabled persons, families and providers
* Approaches are strengths based and are based on achievements/resources within the sector
* It is important to separate *service* and *sector/system* transformation. Points of connection must be explicitly identified but any systems change requires additional in-depth work prior to implementation
* Any changes are built on the premise that individuals and their families will experience *real and informed choice* and that efforts are made to ensure the financial viability of supports and services
* All Ministry actions are consistent with the above

**What this will mean for individuals**

Individuals currently receiving services can remain supported in a similar way if that is their informed choice. Individuals can expect the service to increase their opportunities according to what they like doing, what they want to do more of and new things they want to do. Individuals may choose to spend more time in a greater variety of community activities (employment, social, educational) and the service will be more able to be flexible with this. Individuals will not be forced to do things they do not choose to do i.e. nothing changes unless this is what a person expresses (with appropriate support if necessary).

At some point, some people from outside of the service will come and talk with individuals about what they want to do and get ideas regarding how the service can best support them to achieve what they want to do.

In the future, individuals will be able to have a much bigger range of ways they can get the support they choose.

**What this will mean for families/whānau**

Families, with family members currently receiving services, can remain supported by a similar service if that is their informed choice Families can expect increased conversations with service providers about ideas they have, how the service could improve what they are doing and more information about increased options when *Enabling Good Lives* is further developed.

Families can expect to have the opportunity to be involved in on-going open forums that are considering ways to increase the flexibility of services.

Families will have greater opportunity to attend various events that will enable them to be informed partners e.g. courses on personal planning, Individualised Funding.

In the future, families will have access to an independent facilitator who will be there to assist them to explore options about how funding can be used, express what they want and build the services that will best suit them.

**What this will mean for providers.**

Existing services will complete a self-review and external evaluation process that will form the basis of an “action plan”. This action plan will detail how each service will implement the following between July 2012 and June 2014:

1. move towards a “facilitation approach” to service delivery
2. strengthen natural networks
3. increase individuals access to mainstream services
4. ensure individual costing of supports
5. obtain training, mentoring and/or other supports to successfully action changes

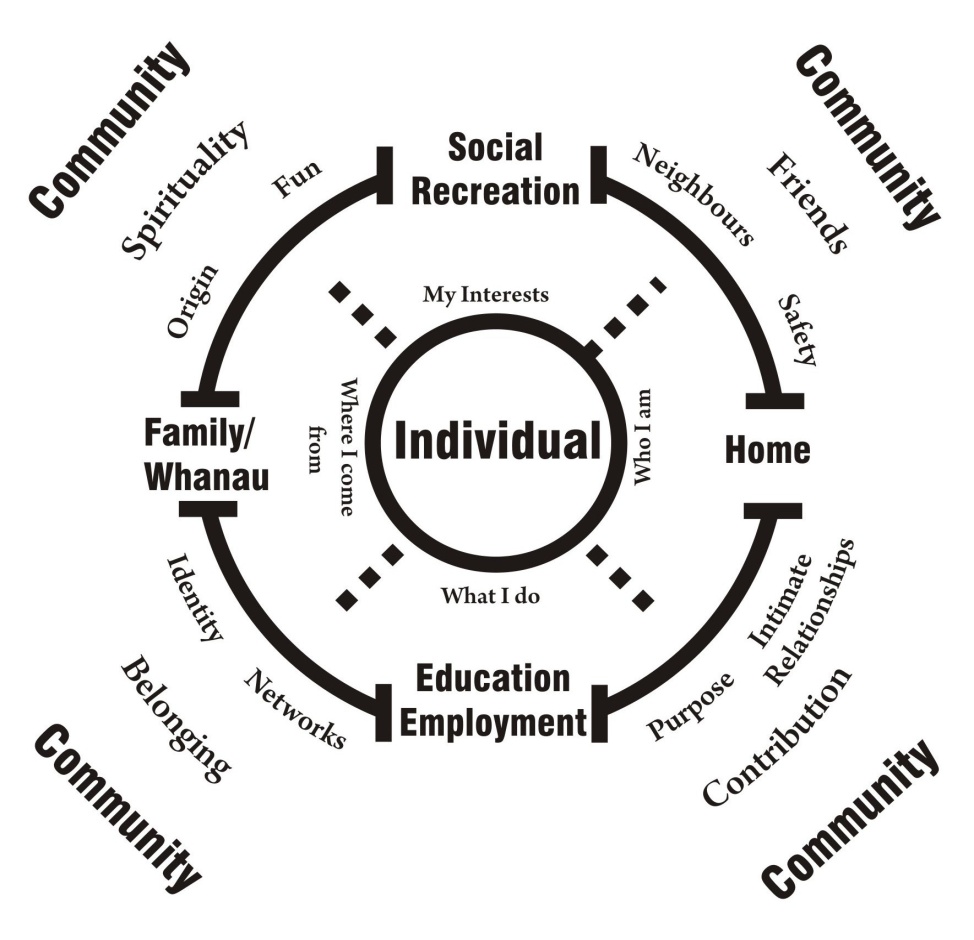
When the new “system” becomes operational:

1. existing services will have the opportunity to “opt-in” up to the point of any new system being introduced
2. access to services will occur through the new individualised funding/independent facilitator process

**What is a “Good Life”?**

Participants in this process identified and agreed experiencing a “good life” was related to the following Figure 1.

**Figure 1 – What is a Good Life**



As with multiple other projects conducted in New Zealand and internationally, a good life was closely associated with:

|  |  |  |
| --- | --- | --- |
| **Being connected with family/whanau** | Having friendships | **Employment** |
| Living where I want with whom I want | **Education** | Contributing to the community |
| **Having fun** | Being valued | **Being able to get around** |

**It was identified during the Enabling Good Lives (Canterbury) project that a “Good Life” could be easier to achieve when: -**

|  |  |
| --- | --- |
| **The “System” will be:** | **How this can happen** |
| Led by the preferences, strengths, aspirations and needs of disabled persons and families | * National and Regional Governance * Aspiration Based Personal Planning being a foundational process for resource allocation and service design |
| Simplified | * One person = one plan across different funding sources * The Independent Facilitator can assist disabled persons and family/whanau to navigate existing options and create new possibilities * Disabled persons and family/whanau have control of funding e.g. bulk funding, according to service type will be replaced with individualised funding where disabled persons and family/whanau can choose how they create a good life for themselves * All Ministries work to the same principles and strategy * There is one process for evaluation and this focuses on how well individuals are able to create good lives and how supports and services can be improved |
| Flexible | * ‘Off the shelf programs’ or ‘service types’ are replaced by an approach where disabled persons and family/whanau receive services crafted to meet their specific preferences and needs |
| Aligned | * All Ministries have a shared point of reference e.g. Enabling Good Lives |

**It was identified during the Enabling Good Lives (Canterbury) project that a “Good Life” could be easier to achieve when: -**

|  |  |
| --- | --- |
| **Supports and services will:** | **How this can happen** |
| Focus on strengthening family/whanau and personal networks | * Operate in a manner that recognises the pivotal importance of family/whanau and personal networks * Assist people to develop personal networks e.g. circles of support * Ensure there is a direct investment into disabled persons and family/whanau networks |
| Operate as facilitators not providers | * Ensure their primary aim is ‘making it easier’ for people to do ‘everyday things in everyday places’ * Educate and encourage local communities |
| Assist people to fully participate in local generic community supports and services | * Explore and implement a range of approaches designed to assist people to develop socially valued roles * Only develop ‘special’ and/or segregated programmes as a time limited last resort or as a response to an identified need/request for specialist services |
| Co-operate with each other | * Emerging good practice is highlighted * Memorandums of Understanding that enable disabled persons and family/whanau to access a mix of providers at the same time |
| Be free to innovate | * Experience less restriction i.e. prescriptive contracts and audit processes replaced with high trust outcomes contracts and development based evaluation |

**There are two distinct transformation pathways:**

1. Existing services – transformation processes can start immediately i.e. from July 2012 **(See Appendix 1)**
2. Changing the whole system **(See Appendix 2)**
3. **Existing MSD and MoH funded Day/Vocational Services**

This transformation process is consistent with expectations contained in the New Zealand Disability Strategy and the United Nations Convention on the Rights for Persons with Disabilities.

Over recent years many organisations and services have adopted or developed approaches that seek to promote equity, inclusion and citizenship for all people. This is reflected in practices that have been strongly promoted and practiced in the last decade to achieve an *individualised* approach promoting social inclusion, collaboration with family/whānau, developing personal networks and utilizing community assets. A core associated belief is that disabled persons and family/whānau are assisted to be self determining.

The Pathway detailed in **Appendix 1** describes how Ministry of Social Development funded Community Participation and Ministry of Health funded day services in Canterbury will be supported to continue the process of enabling disabled persons and family/whānau to create good lives for themselves. All services will obtain a clear understanding regarding what disabled persons and family/whānau want and how they can contribute to making this happen. Service transformation will be guided by the unique preferences and aspirations of disabled persons and family/whānau (as per *Enabling Good Lives*).

This Plan does not prescribe specific service changes. Rather, it establishes clear principles, intent, processes and supports. Specific service changes must be negotiated directly with disabled persons and family/whānau. Real choice is paramount. To predetermine specific changes is contrary to the intent to shift authority to disabled persons and family/whānau, so genuine partnership can be experienced. Considerable service transformation has already occurred over the last decade. This process will build on existing strengths and achievements. It is anticipated that, although all services will have the same principles as a foundation and the same objective (i.e. enabling good lives), individual service approaches will be different as they will reflect the groups of people they serve and the communities they operate in.

Service transformation will be guided and monitored according to the current Developmental Evaluation outcomes framework currently used with Ministry of Social Development funded services.

Associated supports (e.g. training and mentoring) for the development of existing services will be guided by the core skills described in the ‘Tuhana’ resources.

The objective of service transformation is to ensure disabled persons and family/whānau have increased choice and control, services are customised and there are increased opportunities for people to experience everyday things in everyday places. All service transformation processes will be cognisant of the *system* transformation process that will be occurring in parallel.

Initially, the two processes will interface as individuals are transitioning from school (Jan 2013). At this point individuals will access supports and services through an Independent Facilitator. When the Independent Facilitator role is firmly established and systems are fully designed to enable a *whole of life* approach then all new individuals and family/whānau will access supports and services through the Independent Facilitator (target of Jan 2014). At this point, there will be a merging of the transformation processes and individuals, family/whānau and organisations, opting in to the new approach for school leavers will be expected to be joined by all agencies when the new system becomes fully operational.

**Associated Assumptions**

1. This is a natural continuation of the progress associated with *Pathways to Inclusion* and the thinking behind the *New Model for Supporting Disabled People*
2. There are considerable resources currently existing within the sector supporting this *transformation* e.g. existing examples of service transformation that detail *what it takes*, Tuhana research and associated resources, developmental evaluation frameworks and similar approaches
3. Creating, affirming and restoring trusting relationships with family/whānau is critical
4. Developing networks of support is key
5. Developing a working understanding of the principles and skills of facilitation is pivotal
6. Understanding, utilising and strengthening existing community assets is central
7. A “one person at a time” approach builds success
8. Direct investment into disabled persons and family/whānau can enable genuine partnership
9. Existing resources can be used more strategically
10. If people want positive change then it can happen
11. **Changing the whole system**

There was clear support for changing the way that government developed and implemented policies that have an impact on disabled people. Whilst it was agreed that there been good progress in terms of ideas and discussion, generally this hasn’t been seen to be translated into consistently better experiences for disabled persons and their families. The general feeling was things would have to be done quite differently to achieve this. Many disabled persons and family/whanau felt that the timing was increasingly urgent to translate words into action.

Whilst service transformation would help providers to transition to a personalised approach it was widely felt that this would not be sufficient on its own.

The Pathway detailed in **Appendix 2** therefore reflects the wide support for a transformed system based on *Enabling Good Lives.* The resulting system would bearranged around the unique circumstances of individuals, with disabled people and their families engaged at every level of decision making in line with the often quoted “Nothing about us without us” principle.

It endorses a strengths (rather than deficit) based approach to supporting people. Time and again people spoke of the humiliation of believing they needed to display what they, or their relatives, couldn’t do in order to gain access to services.

This Plan advocates for Mainstream options to be considered first. The experience of mainstreaming in schools was cited as an example of creating significant benefits as all children are becoming increasingly accustomed to disabled people being central to community life.

It addresses the need for communities to receive support to enable disabled people to have good lives in mainstream settings. Issues of access, transport, housing and employment are all critical areas that this ‘joined-up’ system could then address.

The Plan also deals with the way government organises its responsibilities and functions. Currently, they are not considered to fit well with the way people live their lives. There is felt to be overlap, confusion and inconsistencies between Ministries which could be overcome if the principles and vision of *Enabling Good Lives* were adopted by everyone - as indicated in the Pathway. This task is not underestimated, which is why it is considered to be hard rather than complicated.

A big challenge is the way different Ministries are geared to undertake their responsibilities. Many are looking at groups of people, service types or whole communities. It takes a shift to a different mind-set to apply things to individual circumstances. The Pathway seeks to address this so that the aspirations and needs of disabled people are considered as part of the mainstream planning system.

Finally, it is also considered that disability could lead the way in supporting the commitment *to ‘*joined-up’government by developing personalised systems and supports. These approaches could then be considered for other areas of health and social policy and practice.

**Figure 2 – The disabled person’s pathway post system transformation**

I want a good life for me/my family member



I have a good, everyday, life in my community

Friends & Family

Learning

Contribution

Community participation

**Independent**

**Facilitator**

**With support I make a plan based on my strengths and the things I want to do in order to have and maintain a good life including identifying who in my family and whanau/friends will help me to achieve this**

Information

Service

Equipment and Modification Services

Someone will help me and talk to me about my life, goals and supports

Someone will tell me how much paid support I can have and what this can be spent on

**Services get money to support my plan**

- Housing

- Equipment, aids, adaptations, assistive technology/telehealth

- Support to live in my home and community of choice

- Respite for me/my family

- Education and training

- Employment and meaningful activity

- Connecting me with my community

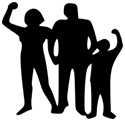
I choose an agency to help me manage my funds

Facilitator/Family/Whanau support to connect me with my community of choice

I need information and/or someone to walk beside me

I need information

I need funded support



I already have a good idea (plan) about what I want to do

I purchase support based on the outcomes of my plan

I can assess my own needs

I need practical help to support my independence

I need funded support

**Governance**

Both the National Networks forum and the Steering Group (Canterbury) believe a significant challenge associated with systems transformation is the configuration of (conditional) authority. It was expressed that actual and sustainable change was only likely if the people with the greatest insight and vested interest participate in key governance roles i.e. disabled persons and families.

With the challenge of designing systems transformation that results in disabled persons and families experiencing greater choice and control, it appeared natural that this is reflected in the composition of a cross-Ministries governance structure. Considerable effort has gone into describing how authority can be shifted on a person by person basis e.g. *Enabling Good Lives* and the Ministry of Health’s *New Model for Supporting Disabled People.* The *Enabling Good Lives* (Canterbury) report proposes that shifting authority must also occur at a systems level.

Service providers are being requested to take more direction from disabled persons and family/whānau. It is considered there is a corresponding need for officials to engage with disabled persons and family/whānau as co-designers, co-facilitators and co-owners of the wider systems change process. Rather than just participating in a variety of *Reference* or *Advisory* Groups, disabled persons and family/whānau are calling for direct involvement in the **shared governance of cross- Ministries system reform.**

As indicated in figure 1 below, the preferred model would see disabled persons and family/whānau having a direct relationship with the Ministerial Committee and central roles on National and Regional Governance groups. It is envisaged that these groups have responsibility for the oversight of service and systems transformation processes and initiatives that involve the Ministries of Social Development, Health and Education. As system reform is integrated then initiatives from other Ministries could be added.

The potential advantage of the proposed Governance structure and Ministries working to a common strategy are multiple. Some of the potential benefits are defined in **Figure 3** below.

It is proposed there are three places where disabled persons and family/whanau will contribute to the development and governance of cross Ministry initiatives and associated change processes. These are the:

|  |  |
| --- | --- |
| **Advisory and Leadership Group** | **Purpose**: To provide information and advice to the Ministerial Committee  **Function**: To ensure disabled persons and their families are represented at the highest level in the design, development and monitoring of initiatives that relate to *Enabling Good Lives*  **Composition:** Predominantly comprised of disabled persons and family/whānau with some common membership between this Group and the National Governance Group |
| **National Governance Group** | **Purpose**: The co-ordination of policy, planning and evaluation across the Ministries of Social Development, Health and Education related to disability supports and services  **Function:** Undertake and commission the design, development and monitoring of initiatives and ensure the alignment of Ministry approaches and initiatives with *Enabling Good Lives*  **Composition:** A citizen board i.e. comprised of Government appointed disabled persons, family/whānau and provider representatives with common membership with both the Leadership and Advisory Group and the Regional Governance Group with official representatives in attendance |
| **Regional Governance Group** | **Purpose:** To oversee the implementation of initiatives  **Function**: To develop and action an annual work plan that ensures all work is ‘joined-up’, responsive to local considerations and adapted according to findings contained in developmental evaluation processes  **Composition:** Comprised of Government appointed disabled persons, family/whānau and provider representatives - with official representatives in attendance. |

**Figure 3 – Governance Diagram**

|  |
| --- |
| **United Nation Convention on the Rights of Persons with Disabilities** |

|  |
| --- |
| **New Zealand Disability Strategy** |

**Ministerial Committee on Disability Issues**

**Enabling Good Lives Leadership and Advisory Group**

**Enabling Good Lives National Governance i.e. Disabled Persons and Family Organisations and Provider Representatives**

|  |
| --- |
| **Cross – Ministry**  **Chief Executives’ Group** |

**MoH**

**MSD**

**MoE**

Governance $

**Regional Governance i.e. Project Based - Implementation**

**Independent**

**Facilitator**

**Potential Benefits of the Proposed Governance Structure and its Implications on Ministries**

Purchase of supports

**Support and Service Initiatives**

|  |  |
| --- | --- |
| Increased satisfaction | Disabled persons and family/whanau interact with clearer and simpler processes |
| Increased control | Disabled persons and family/whanau have direct authority in the design, implementation and monitoring of changes |
| More effective use of funding | Regional Governance Groups are able to successfully target funding as they have greater awareness of local assets, strengths and needs |
| Elimination of duplication | Shared reference points enable the development of single processes that can meet the requirements and needs of multiple Ministries |
| Increased transparency | The Governance Groups have the strategic oversight that will enable them to maximise alignment with the principles and intent of *Enabling Good Lives* |
| Increased accountability | A single process of monitoring and evaluation |
| Better long term planning | A shared frame of reference can result in the greater clarity required for effective planning |
| Strategic capacity building within the public service | Public servants can be better equipped to respond to emerging demands for the public as decision making is located closer to communities |
| Increased potential for innovation | A clear vision and less bureaucratic requirements can create more opportunity for new developments |
| Increased community engagement | Greater access to more local decision makers |
| Shared Authority | Disabled persons, family/whanau and providers are partners with Government |

**Recommendations of the *Enabling Good Lives* (Canterbury) Report for ‘Systems’ (National) and ‘Service’ (Local) transformation:**

**General**

1. **Values** - Adopt or adapt the principles associated within the *Enabling Good Lives* Report as a shared basis for service and systems development
2. **Vision** - Endorse the UN Convention of the Rights for Disabled Persons, the New Zealand Disability Strategy and *Enabling Good Lives* as foundation documents for service and systems development
3. **Purpose** - Approve the use of *Enabling Good Lives* as a basis to develop a framework for a Cross-Government strategic approach to service and sector transformation
4. **Authority** - Support the development of an Advisory and Leadership Group and two governance groups as follows:
   1. ***Advisory and Leadership Group***

**Purpose**: To provide advice to the Ministerial Committee

**Function**: To ensure disabled persons and their families are represented at the highest level in the design, development and monitoring of initiatives that relate to Enabling Good Lives

**Composition:** Predominantly comprised of disabled persons and family/whānau with some common membership between this Group and the National Governance Group

**Funding:** Jointly funded by the Ministries of Social Development, Health and Education

* 1. ***National Governance Group***

**Purpose**: The co-ordination of policy, planning and evaluation across the Ministries of Social Development, Health and Education related to disability supports and services

**Function:** Undertake and commission the design, development and monitoring of initiatives and ensure the alignment of Ministry approaches and initiatives with *Enabling Good Lives*

**Composition:** A citizen board i.e. comprised of Government appointed disabled persons, family/whānau and provider representatives with common membership with both the Leadership and Advisory Group and the Regional Governance Group with official representatives in attendance.

**Funding**: Jointly funded by the Ministries of Social Development, Health and Education

The National Governance Group would report to the Ministerial Committee on Disability Issues

* 1. ***Regional Governance Groups***

**Purpose:** To oversee the implementation of initiatives

**Function**: To develop and action an annual work plan that ensures all work is ‘joined-up’, responsive to local considerations and adapted according to findings contained in developmental evaluation processes

**Composition:** Comprised of Government appointed disabled persons, family/whānau and provider representatives - with official representatives in attendance.

**Funding:** Jointly funded by the Ministries of Social Development, Health and Education

1. **Operational:** Endorse the move towards shared reference points e.g.

5.1 Principles base

* 1. Vision and mission statements

5.3 Unifying strategy

5.4 An across-Ministries leadership team with an implementation focus

5.5 General outcomes framework

5.6 Monitoring and evaluation i.e. a single outcomes focused developmental evaluation approach

5.7 Self directed individualised funding i.e. as proposed in models described in the *Enabling Good Lives*, Canterbury Report and the direction of the *New Model for Supporting Disabled People*

5.8 Aspiration based personal planning i.e. as proposed in the *Enabling Good Lives*, Canterbury Report) and the Choice in Community Living work underway as part of the New Model for Supporting Disabled people

5.9 Independent facilitation i.e. as proposed in the *Enabling Good Lives* ,Canterbury Report and elements of the New Model for Supporting Disabled People work

5.10 A focus on individuals transitioning from school as the starting point for system transformation.

**Service Transformation**

The Ministries: -

6. Endorse the ‘service transformation’ process as described in pages 33-37 of this document

7. Provide timely feedback to Canterbury stakeholder groups

8. Identify existing financial resources, included in current budgets, and transfer them to an *Enabling Good Lives* ‘working budget’ under the proposed Regional Governance Group e.g. a percentage of funding currently administered by Te Pou and New Zealand Federation of Vocational and Support Services

9. Identify ‘untagged’, innovation based or unused funding and commit this to exploring how this can be used in a strategic way to action *Enabling Good Lives* (inclusive of Employment and Canterbury Rebuild initiatives)

10. Establish a Regional Governance Group (as per 4.3 above):

10.1 Consider current *Enabling Good Lives* Steering Group members as core members of the Regional Governance Group

10.2 Consider specific project based specialist working groups (advisory/reference functions) that link with the Regional Governance Group

10.3 Recognise the value of disabled persons, family/whānau and provider members of a Regional Governance groups being both local leaders and representatives of National Networks

10.4 Allocate funding to ensure regular stakeholders forums to enable direct, clear and face to face communication, information sharing and monitoring of initiatives

11. Develop a process to ensure direct investment to disabled persons and family/whānau e.g. principles based skill development by disabled persons and family/whānau for disabled persons and family/whānau

# Appendix 1: Pathway for Service Transformation

**Immediate Steps for Existing Services to move to a ‘Facilitation Based’ Approach**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | What | How | When | Where funding can come from |
| 8.a | Ensure all existing services have the same reference points  a.1- New Zealand Disability Strategy  a.2- United Nation Convention  a.3- *Enabling Good Lives* principles and intent  a.4- Developmental Evaluation outcomes framework | Regional Forums | 2012 |  |
| 8.b | Enable disabled persons and family/whānau to be informed and active partners in service transformation | Direct investment into disabled persons and family organisations | 2012 + | Family/Whānau Carers Support funding, DIAS funding, Te Pou administered Consumer development funding etc. |
| 8.c | All existing services have a service specific *baseline* report i.e. ability to measure qualitative and quantitative change  **Note 1**: services will need to adopt, adapt or create an internal tool and process for collecting information to be used for service monitoring and continuous improvement processes.  **Note 2**: services/organisations can complete, from internal information, a basic ‘national’ questionnaire once every two to three years as part of the external developmental evaluation process. This ‘tool’ will collect core information based on measurable indicators consistent with the Enabling Good Lives principles ( **examples** could be circulated / available on a website for providers)  **Note 3**: the current Outcome Focused Developmental Evaluation Framework can continue to provide a basis for Developmental Evaluation at this stage. Ideally, a general ‘Outcomes Framework’ will be developed and adopted across all funding streams | Implement an agreed self assessment tool and Developmental Evaluation | 2012-2013 | Existing DE funding within MSD and MoH |
| 8.d | All existing services develop an action plan for transformation | Compiled from discussion with disabled persons, family/whānau forums and (B) |  |  |
| 8.e | Contracts are amended to reflect a more flexible approach i.e. ‘service type’ and output measures replaced with outcome measurement | The Enabling Good lives project in the Waitako may inform this |  |  |
| 8.f | A new aspirational personal planning framework is introduced  **Note 1**. This will be based on work currently being undertaken by MoH as part of the New Model for Supporting Disabled People work and similar material used within MSD | Compiled with input from all stakeholder groups | 2012 | Work is underway on this for other projects and will be circulated |
| 8.g | Consideration is given to the interface with other aspects of a person’s life – housing, work, education to ensure all supports and resources are complementary to each other and in line with the aspirational plan | Ongoing work of proposed groups in governance recommendations | 2012 - 2014 | Would need ongoing support of MoH, MSD and MoE |
| 8.h | Existing services purchase ‘support for change’ e.g. customised training and mentoring as required  **Note 1**: There are several existing and several emerging reference points to ensure staff education processes (for service transformation) remain consistent with the principles of *Enabling Good Lives*. Examples of current reference points include the Tuhana based modules (core skills) and current reviews and research have identified specific key skills and tools associated with successful service transformation.  **Note 2**: An additional skills framework can be developed with input from disabled persons, family/whānau, training providers and services currently involved in providing a community based ‘facilitation’ approach  **Note 3**: It is envisaged that the effectiveness of different training approaches and core content is monitored. This information will directly feed into the development of new evidence based generic training e.g. NZQA qualifications | MoH/MSD compile a list of ‘approved’ organisations (that have demonstrated skills) for providers to choose from.  All training and mentoring providers work from same base information e.g. Tuhana, DE ‘outcomes’ and service action plan | 2012-2014 | Existing funding administered by Te Pou, VASS |
| 8.i | Services develop processes to individualise budgets |  | 2014 |  |
| 8.j | Transition from school to work/education/community ‘facilitator’ role in place (LAC type role) | MoH and MSD funding can be combined as per a ‘whole of life’ plan | 2014 | With potential inclusion of MoE |
| 8.k | ‘System’ change integrated |  | 2015 |  |

When the ‘new’ system is in place there will be one plan, one set of guiding principles, one way to enter the system and one set of outcome measures for all services – but choice for individuals and family/whānau.

**Figure 4 – The Service Transformation Journey**

Approx -$7k per Approx $3k per organisation

organisation

Internal and Peer based development

External evaluation –

disabled persons and

family + principles and

funder accountability

Suggest $15k

Training or development purchased from ‘approved’ organisations i.e. approved by EGL governance according to negotiated criteria

**Appendix 2: Pathway for ‘System’ Transformation**

**Immediate Steps for government to take to transform the way supports are designed, implemented and evaluated. Note, these are indicative and will be refined as the process develops**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  | **What** | **How** | **When** | **Where funding can come from** |
| 1 | Respond to *Enabling Good Lives,* Canterbury | Ministerial Committee | 2012 |  |
| 2 | Agree a process for dealing with the recommendations in the Report | Through processes established by the *Enabling Good Lives* Project | 2012 |  |
| 3 | Establish Governance Arrangements | * Recruitment strategy * Terms of reference * Implications for Advisory/Reference Groups | 2012 | Existing funding within MSD and MoH |
| 4 | Agree process for establishing a cross-Ministry, strengths based, person-directed planning framework | * Collate different approaches * Work through impact on contracts, purchasing and evaluation processes | 2012 |  |
| 5 | Agree process for developing the Independent Facilitation approach in Canterbury | * Through regional/local governance | To be in place by Jan 2013 |  |
| 6 | Develop local communication plan | * Through regional/local governance * Build capacity through local ‘hubs’ * Establish provider forums to establish collaborative approach and plan for shared resources. Purpose: share successes * Ministries of Health and Social Development to write to every individual, family and provider detailing EGL and transformation process – a clear and comprehensive ‘instruction manual’ |  | DIAS contract adaptation?  Funding from Te Pou – leadership development? |
| 7 | Lead a process that ensures clear and direct consultation with all concerned stakeholders (clarity, reassurance and independent information) | * Through regional/local governance – an adaptation of local Steering Group. * Selected members of the Steering Group identified as EGL leaders who may host six monthly forums with disabled persons, families and providers (as determined by the governance group). |  | Funding from Te Pou – consumer leadership development? |
| 8 | Establish a transparent and co-operative approach | * Providers to develop and action clear communication plan and communication with people with moderate to severe intellectual disability |  | Existing via NZDSN, ASENZ and VASS |
| 9 | Obtain clarity and reassurance regarding sustainability of funding | * Ministries of Health and Social Development to combine funding streams in an open and transparent manner |  |  |
| 10 | Evaluation and training resources become aligned to Enabling Good Lives | * Disabled persons, family and providers participate in the defining of facilitator role and associated training (possibly via governance group) * Identify organisations and strategies that demonstrate progress in relation to *Enabling Good Lives* (possibly via the internal review and external evaluation process) * Canterbury based training reviewed to ensure consistency with *Enabling Good Lives*. Training explicitly linked to EGL given priority |  | Prioritise the allocation of existing evaluation resource within Ministries of Health and Social Development  Te Pou and VASS administered funding, for leadership and training, to be ring fenced and targeted with a fair proportion (by e.g. percentage of population of national training budgets shifted to an EGL *Enabling Good Lives* fund? |
| 11 | Ensure diversity and flexibility | * Individuals and families supported to imagine options i.e. direct investment of funds to disabled persons and family development * All persons (in services) to have an aspiration based personal plan |  | Existing Te Pou funding, Family/Whānau Carers Support Courses reprioritised and other existing sources  Existing expectation for MSD funded services. Explore how current NASC funding can be ‘shifted’ to an aspiration based planning approach and independent facilitation model |
|  | Identify associated issues/implications | * Examine how *Enabling Good Lives* links with the Canterbury Rebuild, Ministry of Health New Model for Supporting Disabled People, Education, Social Housing and Employment initiatives. Develop a unified and inclusive strategy based on shared principles and general outcomes. National and Regional processes to ensure linkages * Develop strategies that ensure people are not placed into situations where they are worse off (lost networks and friendships) |  | As co-developed by Ministries of Health and Social Development with Disabled Persons and Families |
|  | Contribute to principles based model coherency reviews | * Planned developmental evaluation |  |  |
|  | ‘System’ change integrated | * Develop new systems – whole of life focus * Adapt existing funding processes * Ensure support systems for all stakeholders * Developmental evaluation – service by service transformation plans plus system transformation review * ‘Opt in’ processes actioned | July 2013 – June 2015 |  |
|  | Embed Transformation | * New ‘systems’ and practices fully implemented * New systems fully operational – facilitation focus and community is the ‘default’ * Work, home and community focus * Concepts and language reinforced e.g. diversity, equity, citizenship, contribution and human rights   Examples of successful self direct funding and customised services able to inform development in other health and social services | July 2015 – June 2016 |  |

When the ‘new’ system is in place there will be one plan, one set of guiding principles, one way to enter the system and one set of outcome measures for all services – but choice for individuals and family/whānau

|  |  |
| --- | --- |
| **Service Transformation – Appendix 1** | **Sector Transformation – Appendix 2** |
| Same points of reference | Transparent + co-operative approach |
| Invest in disabled persons and families | Co-development |
| Baseline | Sustainability |
| Project Plan | Programme Plan |
| Flexible Contracts | Develop new systems |
| Aspiration Based Personal Planning | Adopted through life milestones and across Ministries |
| Whole of Life approach | Joined-up Government |
| Customised Training | Developmental Evaluation |
| Individualise Budgets | Personalisation across Ministries |
| Transition entry to services (opt-in) | Initial implementation |
|  |  |
| Independent Facilitation entry to all services | System integrated |
| New system operates for everyone |  |

**Figure 5 - Independent Facilitation – How it could work**

Independent Facilitator/LA

Indicative Funding i.e. Self Assessment

Independent Facilitator

Independent Facilitator

NASC

Plan = access to all services

Independent Facilitator

**Appendix 3: Enabling Good Lives - General Overview**

**Context**

In January 2012 the *Enabling Good Lives* report was released. This report proposed that the current centre-based model for day and community participation services be incrementally transitioned to a facilitation-based support model. The focus of facilitation-based support would be on enabling disabled persons to do ‘everyday things in everyday places’ in communities, rather than on provision of ‘special’ places or activities for disabled people. It would include support funding from across government agencies that would be individualised and flexible.

**Principles**

The Canterbury Steering Group endorsed the set of ten principles designed by the *Enabling Good Lives* Working Group to underpin future disability supports. (These are contained in **Appendix** 5).

There was consensus that the current system could not accommodate these principles. There was a lot of discussion about what is wrong with the way it works at present but also a real concern that it was so complicated even when looking at just the two Ministries who have taken a lead in this, let alone bringing in others. Yet, the prevailing view was that it could be better if only the silos could be dismantled and the power around choice and control shifted significantly to disabled persons and their families

To balance this, a further principle of *Do no harm!* was introduced as a timely reminder that significant changes such as those proposed bring risks and so it would be important to ensure there were safeguards developed for people throughout the transformation process.

There was also recognition that a number of Canterbury day provider agencies were already working to similar principles and designing personalised services within the constraints of contracts and monitoring arrangements

This led to the twin-track approach to getting to a position where Canterbury could measure well against the *Enabling Good Lives* principles:

* First there would be a process to test the commitment of provider agencies (who, after all, hold the resources to deliver day and community participation services) for each to then create an action plan to assist with the achievement of *Enabling Good Lives* and to have their initial self-assessment and progress against this externally validated
* Second, and in parallel to this, it was felt that the much bigger system redesign should be called for. It should test the appetite for shifting power from government to disabled persons and their families. There was support for a whole of life approach that adhered to cultural integrity. It was strongly felt that if the powers that be wanted it to happen then it could but the strengths of people and organisations with vested interests would mean it would not be an easy road to travel. Hence, if it didn’t happen as proposed, at least the first track would edge services and some systems in the right direction. It would also send clear signals to the market about what was likely to be supported in the future and what wouldn’t be.
* Finally, it was agreed that this approach should apply to everyone regardless of degree of disability. Indeed, for people without a voice, all the more need to ensure that supports are designed to enable them do the things that they really want to, in a place, a time and in the manner that they choose and are comfortable with, In short, to enable a good life!

## What facilitation-based support would look like

The facilitation-based support model would actively support disabled people to have an everyday life in everyday *places*. It would support people to achieve desirable outcomes such as education and training, employment, being with friends, having relationships and a family, taking part in community and cultural activities.

Key differences from the current system would be that:

* Government support would facilitate participation and inclusion in employment, mainstream community activities and social networks, rather than mainly providing centre-based activities
* People would be supported to build plans that built on what they can and like to do and their aspirations (which are likely to grow with opportunity)
* People (with their family/whānau) would then have more choice and control over the supports they use, in order to achieve their plan, rather than simply being allocated a specified service
* Natural supports and mainstream services and resources would be first choice - before specialised disability supports
* A person’s day and week would therefore be likely to be made up of a range of different types of activities built around their stated preferences, not a generic day programme
* Divisions between current programmes would diminish, so a single entry type of arrangement could cover supports across day and night, employment support (e.g. business enterprises and supported employment), home support and community participation.
* Crucially, resources would flow person by person and not via block grants

**Key Elements of Enabling Good Lives**

* ***Self-directed planning & facilitation*:** a skilled facilitator chosen by the disabled person would assist him or her to build and maintain relationships and support networks in the community, access mainstream community-based services and activities, and identify opportunities to contribute to the community. The facilitator would help the person to identify their aspirations and goals, and develop a plan to achieve them. The level and duration of facilitation support would vary for each person.

The facilitation role would be independent from both funding allocation and direct service provision (e.g. support with personal care, mobility assistance). It would be a joint agency initiative (potentially the Ministry of Health and Ministry of Social Development). There would be regular independent external evaluation to ensure that the facilitator is being responsive to the individual/families within a reasonable timeframe.

* ***Cross-government individualised/portable funding:*** an individual allocation of funding would be available to the disabled person, potentially on a self-directed basis. This would require all current disability support funding the person (and their informal carers) attracts to be identified, (e.g. day service, community participation, home and community support service, individualised funding, residential, supported living) and ’unpacked’ where this is possible.
* ***Strengthening families/whānau*:** Families/whānau would be supported to assist the disabled person (e.g. by promoting family-to-family support, and family and whānau collectives). There would be separate funding support for family carers to build integrity into the system, cultivate natural supports, and distinguish the legitimate (but sometimes competing) needs of the individual and family.
* ***Community building:*** mainstream organisations would be supported to address barriers to inclusion that disabled people face e.g.: the physical environment and attitudes of employers, government agencies etc. Most of this work would be done by the facilitator or providers who are enabling people to participate in the community. There may also be support from general disability funding, specific initiatives or employing ’change agents’.

## How it would work

The disabled person (and family/whānau) would choose a facilitator to support them in a self-directed planning process. (There would be some clear criteria to ensure that the facilitator has appropriate skills and experience). The facilitator would help the person to identify their aspirations and goals, and develop a plan to achieve them. The plan would identify available community resources and other natural supports (e.g. family, friends etc.) but may also suggest areas that need additional resource or funding. The facilitator would also advocate for other government-funded supports, if required. The plan would be seen as legitimate by all agencies.

**Figure 6:Overview of facilitation-based support model**

**Community building**

Organisations and communities are supported to address barriers to inclusion, eg: the built environment, attitudes of employers, government agencies etc.

**Building an everyday life for me and my whānau**

**Planning and facilitation**

A skilled facilitator assists the disabled person (with family/whānau) to identify aspirations and goals and how to achieve them, helps build relationships and social networks, access community-based services and facilitates participation and contribution in the community.

**Individualised/portable funding**

Combine funding from agencies. Allocate small amounts to all at a flat rate, with more for those with higher needs. This funding could be self-directed.

**Strengthening families and whānau**

Families/whānau are supported to assist the disabled person (eg promoting family-to-family support, and family and whānau collectives. There would be separate funding support for family carers.

**Appendix 4: Testing congruence with the NZ Disability Strategy**

Along with other New Zealanders, disabled people aspire to a good life.

The vision of this Plan is a fully inclusive society. New Zealand will be inclusive when people with impairments can say they live in:

‘A society that highly values our lives and continually enhances our full participation.’

This will happen in a country where:

1. disabled people have a meaningful **partnership** with Government, communities and support agencies, based on respect and equality
2. we have moved forward from exclusion, tolerance and no accommodation of disabled people to a fully **inclusive and mutually supportive** society
3. disabled people are integrated into community life on their own terms. This means that **equal opportunities are assured but individual choices** are available and respected
4. the **abilities** of disabled people are valued and not questioned
5. **interdependence** is recognised and valued, especially the important relationships between disabled people and their families, friends, whänau and other people who provide support
6. human rights are protected as a fundamental cornerstone of government policy and practice
7. the diversity of disabled people, including their cultural backgrounds, is recognised, and there is flexibility to support their **differing aspirations and goals**
8. disabled people are **treated equitably**, regardless of gender, age, cultural background, type of impairment or when and how the impairment was acquired
9. community-based services ensure that disabled people are supported to live in their own communities, and institutionalisation is eliminated
10. the idea that society imposes many of the disabling barriers faced by people with impairments is widely understood and, therefore, legislation, policy and other activities enhance rather than disable the lives of people with impairments
11. the principles of the Treaty of Waitangi are recognised.

**New Zealand Disability Strategy Objective 7**: **Create long-term support systems centred on the individual**

1. Create a quality assessment and service delivery system that is centred on disabled people, ensures their participation in assessment and service delivery, has invisible borders and is easy to access.

**Appendix 5: Ten Principles endorsed by The Canterbury Steering Group**

* ***Self determination - tino rangitiratanga*:** disabled people are in control of their lives, and supports are tailored around their interests, preferences and goals.
* ***Whole of life:*** supports are designed to take a whole of life approach (ie people’s lives are not compartmentalised into day, night, home, community etc).
* ***Ordinary life outcomes*:** disabled people and their family/whānau are supported to imagine what a good life might look like and how this can be achieved. They have opportunities to work, contribute, learn, have relationships, have a family, have a home, take part in their culture and participate in recreation and sport - like others at similar stages of life.
* ***Mana enhancing:*** empowerment: values the contributions of disabled people and their families, and ensures support provided empowers them – ie support should be invisible, not diminishing mana.
* ***Mainstream is the default:*** community based or generic supports are made accessible and available to disabled people before separate disability supports are provided.
* ***Kotahitanga tatou – whānaungatanga:*** supports are based around relationships - a unified partnership connecting disabled people and their family and whānau with communities, building supportive relationships, and encouraging community responsibility.
* **Manaakitanga *- Community building*:** engage and support communities to be more welcoming and inclusive of disabled people – create accessible communities.
* ***Simplicity*:** supports are simple, easy to access, are the least restrictive they can be, and make things easier for the disabled person.
* ***Timatanga (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, skilled adults.
* ***Flexibility:*** supports meet the continuum of need and are responsive to people’s changing needs and aspirations over time.

**Appendix 6: Definitions**

|  |  |
| --- | --- |
| **Personal Plan** | A plan developed by an individual and/or families based on their preferences, strengths and aspirations. The personal plan describes what a ‘good life’ looks like for the individual and is holistic in nature e.g. would include comment related to work, education, living situation and social areas. The purpose of a personal plan is to enable individuals and their families to provide clear direction related to preferences and aspirations and how supports and services may contribute to this.  Notes:  a)different formats and communication approaches will be needed to ensure relevance  b) individuals and their families may choose to obtain support in the development of the plan  c) although different formats may be used and different people may facilitate the development of a “plan”, ALL plans will be developed according to the same principles and will contain the same components  d) services may need to negotiate with individuals and families regarding how they will effectively contribute to people achieving their aspirations  e) personal plans will change over time and there is experience that some people aim too low due to their limited experiences. It follows that as the system gets more skilled at supporting people to achieve a better life, so the aspirations for others will be enhanced |
| **Facilitation** | A way of working that focuses on how to make it easier for individuals and families to achieve their aspirations. Rather than primarily focussing on what a service can provide to/for an individual or family, a facilitation based approach requires services to explore a range of options e.g. natural networks, existing community options. A facilitation based approach can include a direct contribution a specialist service may make.  *Enabling Good Lives* promotes the concept that ALL supports and services will operate in a manner consistent with the stated principles and intent of the *Enabling Good Lives* Report. |
| **Independent Facilitator** | A role where the person’s (i.e. Independent Facilitator) primary connection and allegiance is with the individual and/or their family.  **The intention of the Independent Facilitator role includes ensuring:**   * natural supports/networks are acknowledged and strengthened * “paid” support makes life easier for individuals and family/whānau * community resources are able to be effectively access by all citizens * services do not provide something that can be accessed through family/whānau and/or the wider community * resources are co-ordinated * individuals and family/whānau have maximum control of supports and services * supports and services are driven by the preferences and aspirations of individuals and family/whānau |
| **Service Transformation** | The process of change, associated with specific existing services recognising that we are starting from where we are now and transitioning to where we want to get to |
| **System Transformation** | The process of change, associated with disability and other social service systems which is a much wider and more complex exercise |
| **Outcome** | The results of supports/services/outputs i.e. what has happened because of what you have done (i.e. the difference made). Often subjective and qualitative e.g. increased confidence, stronger identity but can also be objective and measurable e.g. status, control over funds, choice of supports etc |
| **Outputs** | What is actually delivered for the money expended and can be quantified e.g. number of people supported into employment, number and type of qualifications, the number of courses held etc |

**Appendix 7: Indicative Costing – EGL Service Transformation Process**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
|  |  | Internal Review and Action Plan | External Evaluation | Purchasing Supports i.e. training, coaching | Total |
| **MSD and MoH Funded Services (note: this may not be a complete list)** |  |  |  |  |  |
| Hohepa (Canterbury) | CP | 3 | 7 | 15 | 25 |
| SPAN (Skillwise) | CP | 3 | 7 | 15 | 25 |
| Step Ahead Trust | CP | 3 | 7 | 15 | 25 |
| Canterbury PARAFED | CP | 3 | 7 | 15 | 25 |
| Handmade Studio Trust | CP | 3 | 7 | 15 | 25 |
| Helen Anderson Trust | CP | 3 | 7 | 15 | 25 |
| Te Maramatanga Ki Otautahi Trust | CP | 3 | 7 | 15 | 25 |
| Chris Ruth Centre | CP | 3 | 7 | 15 | 25 |
| Alpha | CP | 3 | 7 | 15 | 25 |
| Horizons | CP | 3 | 7 | 15 | 25 |
| IDEA Services x 8 sites |  | 24? | 56? | 120? | 200? |
|  |  |  |  |  |  |
| The Richmond Fellowship of New Zealand | SE | 3 | 7 | 15 | 25 |
| Comcare Charitable Trust | SE | 3 | 7 | 15 | 25 |
| Catapult | SE | 3 | 7 | 15 | 25 |
|  |  |  |  |  |  |
| Kilmarnock Enterprises Inc | BE | 3 | 7 | 15 | 25 |
|  |  | 42 + 24(?)  66 | 98 + 56 (?)  154 | 210 + 120 (?)  330 |  |
| Year 1 |  | 22 | 52 | 110 | 184 |
| Year 2 |  | 22 | 52 | 110 | 184 |
| Year 3 |  | 22 | 52 | 110 | 184 |
|  |  |  |  |  |  |
|  |  |  |  |  |  |

**Appendix 8: Safeguards**

|  |  |  |
| --- | --- | --- |
| **Who** | **What** | **How** |
| National Governance of Systems Transformation | Intentional design, strategy and high level monitoring | Ensure Model Coherency i.e. all initiatives align with the principles and stated intent of Enabling Good Lives |
| Regional Governance | Project based implementation oversight | Outcome Mapping i.e. ensure involvement of key partners and the development and monitoring of clear progress indicators |
| External Evaluation | Developmental Evaluation to ensure early identification of challenges and strategy development | Disabled persons and families have key roles in implementing and contributing to regular evaluation |
| Independent Facilitator (LAC) Role | Independent ally of disabled persons and family/whānau | Consistent on the ground monitoring and advocacy |
| Involvement of National Networks in National and Regional Governance | Mandated involvement, accountability and transparency | Clear and consistent messages to highlight emerging good practice and areas of concern |

**Appendix 9: General Quality of Life Outcomes Framework**

|  |  |
| --- | --- |
| **Area** | **Individual Outcomes – in relation to contact with supports and services** |
| **Autonomy**  (Self determination) | * Individuals believe the service tries to understand them. * Individuals have control over their lives. * Individuals make informed choices e.g.   where they live,  who they live with,  opportunities for employment, involvement in their community and access to relevant education and training |
| **Natural Authority**  (Control over services) | * Individuals have a range of opportunities to influence policies, practices and activities in the service. * Individuals contribute to the regular evaluation of services. |
| **Identity**  (Personal Development) | * Individuals are encouraged to develop and express their identity. * Individuals have opportunity to explore their personal growth and are able to imagine and strive toward a truly good life. * Individuals experience fulfilment in their lives. * Individuals’ personal information is regarded as confidential. |
| **Belonging** | * Individuals participate in a range of educational, social, recreational, employment and/or personal activities in the community. * Individuals are connected with supportive natural networks. * Individual are able to contribute to the community. * Individuals have a range of roles that are socially valued. |
| **Customised Supports** | * Individuals experience resources and supports that are customised to meet their expressed aspirations, preferences and needs. * Individuals experience the service as encouraging and enabling. * Individual experience that achieving their aspirations is easier through contact with the service. |
| **Opportunity** | * Individuals experience opportunities for gaining new skills and qualifications and economic advancement * Individuals contribute to the community. |
| **Partnership** | * Individuals are respected as partners. |
| **Safety** | * Individuals experience the service as reliable. * Individuals are safe. * Individuals are supported to take risks. |

**Appendix 10: Acknowledgements to contributors**

Many individuals and organisations contributed to the *Enabling Good Lives* in Canterbury project. The Compilers would like to thank everyone who made the time to get involved and discuss, debate, challenge and otherwise participate in the process. There are too many to mention individually, although the list below is of people who were involved in the three stakeholder groups. The outcome is all the richer for the contributions from everyone particular from disabled persons and families who haven’t always had the opportunities for their voices to be heard. Thanks also to Richard Buchanan, Rebekah McCullough, Hannah Perry and Gabielle Venz for facilitating the stakeholder meetings so ably and to Teresa Evans-Turner for a lot of background work and administration support.

**Canterbury Steering Group Members/Participants (and who they represented)**

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**National Network Members:**

Andrea Lee (Families/ Parent to Parent); Anne Wilkinson (Families/ Parent to Parent); Cindy Johns (Disabled persons/People First); Claire Stewart (Disabled Persons/Advocacy); Craig Hutchinson (Funders/NASCA); John Grant/Tess Cassey (Providers/VASS); John Taylor/Clare Teague (Providers/NZDSN) Marsha Marshall (Facilitation/Manawanui in Charge); Matt Frost/Wendi Wicks (Disabled Persons/DPA).

**Officials Group Members**:

Alison Riseborough (MSD Policy); Anne O’Connell/Murray Penman (MoH Operations); Gordon Pryde (MSD Operations); John Wilkinson (MoH Policy); Sandra Moore (MSD Policy)

**Appendix 11: What does a facilitation-based support model look like?**

**Comparisons**

|  |  |  |
| --- | --- | --- |
| **Common words in a ‘provider based’ approach** |  | **Common words in a ‘facilitation based’ approach** |
| Care | **..............................................** | **Contribution** |
| Standardised | **..............................................** | **Customised** |
| Equality | **..............................................** | **Equity** |
| Service performance | **..............................................** | **Individual and family outcomes** |
| ‘Provision’ | **..............................................** | **‘Making it easier’** |
| Programme | **..............................................** | **Tailored supports and services** |
| Need | **..............................................** | **Aspiration** |

|  |  |
| --- | --- |
| **Key questions asked in a ‘provider’ based approach** | **Key questions asked in a ‘facilitation’ based approach** |
| * What can we give to you or do for you? | * **How can we ‘make it easier’ for you to get what you want or need?** |
| * What programmes or activities do we need to develop (internal focus)? | * **How can we enable you to obtain what you want or need (external focus e.g. natural networks, community supports and services)?** |
| * What do you need (individualistic and potentially a deficit focus)? | * **What do you and your network want (inclusive of family and support network with a preference and aspiration focus)?** |
| * How can we meet your needs (focus on service based actions)? | * **How can we best contribute to your needs being met (focus on positively influencing others)?** |
| * This is what we offer – what best meets your needs (‘off the shelf’ services)? | * **How can we create supports and services that enable you to build a good life for yourself (customised services)?** |

**In a facilitation based support model emphasis is placed on the following service behaviours:**

|  |  |
| --- | --- |
| **Mana Enhancing** | The way the facilitator interacts with people enables them to develop/maintain dignity and be/remain strong - even if people have different perspectives! |
| **Casual** (not formal) | Facilitators approach things in a relaxed and flexible manner |
| **Reading Clues** | The facilitator pays close attention to subtle detail |
| **Fairness** | Equity is obvious as supports and services reflect the unique strengths, preferences, needs and aspirations of individuals and their families |
| **Flexibility** | Making changes is seen as a predictable and natural process |
| **Innovation** | The facilitator appeals to people to develop new ways of approaching things |
| **Positive Influencing** | Seeking to expand opportunities by educating and encouraging changes in the behaviour of individuals and organisations that can make a positive difference |
| **Obtaining trust through experience** (not role/position) | Developing trusting and mutual relationships is a priority task |
| **Creating space** | Building environments and situations where individuals can ‘step up’ and experience achievement |
| **Paying attention to effectiveness** | A constant process of observation where supports and services are either affirmed or adapted |

.

**Appendix 12: Specific staff skills associated with a facilitation-based support model**

1. **Interpersonal Communication Skills**

* Creating safe environments
* Open questions
* Perception Checking (understanding accurately)
* Positive Reframing (turning ‘problems’ into possibilities)
* Variety of communication techniques (e.g. ‘talking mats’)

1. **Conflict Management**

* Win/win concepts and practices (negotiation skills)
* Meeting conflict constructively
* Appreciating diversity

1. **Networking**

* Local knowledge (e.g. community mapping, asset registers)
* Developing relationships i.e. family/whānau, generic resources and allied social/human services

1. **Strategic Planning**

* Environmental analysis
* Task Analysis i.e. breaking things down into achievable steps
* Asset development e.g. community, person, staff, family and systems

1. **Matchmaking**

* Developing connections

1. **Cultural Competency**

* Informed and respectful ways of working

1. **Optimism**

* Strengthens Based Practice

**Appendix 13: How will a facilitation-based support model make a positive difference?**

The following material has been adapted from **“***Effective Practice in Community Participation Services: A New Zealand Experience”*

|  |  |  |
| --- | --- | --- |
| **What** | **How this is done?** | **Practical Examples** |
| 1. **1. Assist the development of trusting relationships** | * “making the time” to learn about an individual’s preferences, strengths and goals * Becoming familiar with an individual’s natural supports (family/whānau and friends) * Ensure that the individual moves at their own pace * Respect people’s space | * Engage in casual conversation and “no pressure” initial contact * Personal planning * Create ongoing opportunities for each individual to engage * Acknowledge and accentuate what the client “can” do * Respect each others opinions and personal values – we don’t always have to agree but we can show respect |
| 1. **2. Structuring opportunities for people to succeed** | * Expose individuals to lots of different opportunities and experiences – then find out what interests/excites people. Give people things to do that they can be successful with - then encourage them to choose what they will do * Break big things down into smaller steps and identify who will do what * Encourage/acknowledge * Highlight peer achievements | * Watch for what excites people then encourage them to do it for themselves/for others * Pay enough attention to what people are doing so that you can describe/reflect progress/achievement * Regularly recognize and celebrate with groups in a tangible and valued way e.g. special morning tea |
| **3. Assisting individuals and families to “take more control”** | * Discussions where people determine what they want to be involved in – individuals experience that their opinions immediately translate into service actions * Encourage participation by sharing responsibilities * When a trusting relationship has been developed, deliberately shift responsibility i.e. you want it = you do it * Atmosphere characterized by a mix of respect and mutual “joking” i.e. not “therapeutic” but fun! * Staff awareness of “power and control” dynamics” | * Clarity about “staff” purpose i.e. facilitator = I am only here to make it easier for you to do what you want to do – not do it for you. * Create task sheets and document who is doing what and the time frames * Use strengths-based / empowering language eg “it’s your responsibility”, “you do it”, “what has that taught you?” |
| **4. Increasing knowledge of what exists** | * Know what is “out there” * Link individuals/groups with the right person/activity/group in the community (not duplicating/replicating or creating a “special” version * Reflective practice i.e. what did you learn from that?, what can we do differently next time? * Adapt approaches and activities for each individual and situation | * Gather accurate and current information about community resources * “match” people to each other * Observe and “feel” individuals energy and interest levels … be flexible and keep it fun |
| **5. Creating a clear vision and purpose** | * Shared “principles” as a foundation * Shared “outcomes” * negotiate on an ongoing basis. * strong values base | * constantly asking ‘why are we here? and “What is our purpose? * Key values for … are self-determination, learning, inclusion and *innovation* * Driven from the “bottom up” e.g. external facilitation of service user and family input into strategic plan * Ensuring service provision is based on client goals and aspirations in meaningful and demonstrable ways. * Values always inform/guide decision making and service objectives and outcomes * An “open mind” is important |
| **6. Affirming or developing strong leadership** | * Ensuring leadership “style” embody the values and principles associated with Enabling Good Lives * meaningful conversations with all involved parties | * engaging people and bringing them together * Listen * Be flexible: constantly changing and adapting to meet needs * encourage staff to be passionate and professional * Shape roles according to staff member’s skills, interests, strengths * Planning week every four months. Time to reflect and review, set team goals, involve everyone, ask them what they think and so are invested in outcomes. * Support staff receive external supervision * Emphasis on targeted and customised staff training * Change organizational structure to make best use of staff resource e.g. “non-scheduled” |
| **7. Finding out what people want more effectively (see “personal planning section”)** | * Casual conversation and observation are the key | * Spend 3 months where person gets used to the organisation and what is on offer before doing a personal plan. People are then clearer about their options. * Use “tasters” i.e. exposure to different experiences * Involve and engage the important people in an individuals/families life |
| **8. Individualised Service Delivery** | * ask the person what they would like a build services around this | * Nothing is set in stone * All staff engage with individuals * Regular reviews of personal plans – formal and documented * Personal plans contribute to the organisation’s strategic planning process * Quality comes from the conversational, informal discussions – know the person * Value people, look for opportunities, be open-minded |
| **9. Increased Partnerships** | * Working collaboratively * Constantly looking for opportunities outside of disability sector – focus on community | * Create opportunities for people to have meaningful connections * Get to know the right people * Know what’s available in the community and use it – don’t reinvent wheel * Be clear about outcomes – ‘enjoyment’ is a relevant outcome * Constant communication – checking in |
| **10. Expand a “broker role”** | * linking people in to outside opportunities * “out of hours” support * Assist people in “joining the dots” | * Process for person engaging with community may start in-house – small steps * “Moving people along the continuum” (from trying activities in safe, segregated setting to mainstream ). * Regular activity – creates familiarity, everyone becomes comfortable * No Exceptions Action Plan * Know it’s going to be hard work - a journey * Need to overcome ‘fear’ factor in community – prepare them, give them strategies to engage with the clients, tell them why people want to be part of the activity. * “Broker” helps create opportunity but structures it so that the individual/family has to be active in making it happen.   “I will do this, and you need to do this”.   * Pre-planning, ‘no surprises’ * Finding right person in right organisation to work with |
| **11.Strengthen the “Interpreter” Role** | * Paying close attention to what individuals are expressing, ***through actions, reactions and discussions*** | * Gather information-interpret-act-adapt * Occurs on a formal and informal basis |
| **12. Expanded good relationships in the community** | * Location – right in the middle of things * Network * Help people with the change process * Restore, develop or affirm good relationships with families * Become a community asset | * Problem-solve through networking * Building up connections in community – creates momentum, one thing leads to another * Recognize some people have never been given opportunity to do things differently (at the persons preference and pace) * Familiarise people with the concept of change * Show each individual what it will mean for them and provide individualised support * Trusting relationships help * Take time * Recognise that families can be fearful and protective and work with them – reassure them and build up trust * take little steps. Peer success and watching others has helped |

**Appendix 14: Aspiration Based Personal Planning**

Many people do not learn the skills necessary to translate their aspirations into something real, constructive and achievable.

Personal Planning is a simple format used to teach people how to take some control of their life today in a way where they are building their dreams for the future.

|  |
| --- |
| **Aspiration based personal planning sets the direction.**  Services may need to negotiate with the individual and family further to develop an additional set of steps that describes the specific contributions they will make to assisting a person/family create good lives for themselves (this is not a personal plan – but, a service plan that may explain strategies/“how”) |

The purpose of a personal planning process is to assist people to get better lives.

The personal planning process includes many different aspects of personal and skill based learning.

It is a framework to develop:

* Communication Skills
* Decision making Skills
* Planning Skills
* Confidence
* Partnership with a service provider

The planning process is as much about people learning to take control of their lives as it is about creating a piece of paper.

The following diagrams explain the aspiration based personal planning process

**Building a Good life**

**THE ESSENCE OF AN ASPIRATION BASED PERSONAL PLANNING PROCESS**

**A Planning Process for Individuals who have High Support Needs**

A communication system and known preferences

Identify HOW the person communicates, and what method of communication works best for that individual. Almost without exception the best people to help answer this question will be the individual’s family, caregiver or any other significant person who has known them for a long period.

For individuals to grow they need to be exposed to new experiences that are consistent with what you know are their existing (or possible) preferences. Many people with high support needs have had limited experiences in life and exposure to new experiences that fit in with known preferences will help determine future activities.

We can observe the individual’s responses to these new experiences and determine which ones can be pursued or discarded for the present i.e. affirm or adapt.

We can now refine supports and services on the basis of our observations.

Following a simple process like this enables people with high support needs to have direct control and influence over the things they are involved with.

Support staff no longer have to guess at what would be “good” or beneficial for the individual but have actual information (communicated by the service user) about what the person likes, dislikes and wants.

It is true that some individuals may not be in a position to “state their aspirations”, in a way that we can easily understand, but it is possible for support staff to set things up in a way that ensures service users have a central place in decision making about what they are doing.

**Appendix 15: Key Messages from Stakeholder Forums**

The principles for ‘Enabling Good Lives’ have been widely endorsed

* 1. The general intent of ‘Enabling Good Lives’ has been supported
  2. **ALL** groups have independently raised the following points:
     1. All stakeholders groups want **central involvement in design** i.e. the project is led by the sector
     2. It is a **whole of system change** - not just one aspect
     3. **Start early** ( EGL principle:Timatanga -beginning early) is strongly endorsed
     4. **‘Enabling Good Lives’ could potentially provide a framework** for other work in the sector e.g. Demonstration Projects for ‘Local Area Coordination’, ‘Choice in Community Living’, ‘Going Places’ etc. as well as the wider Welfare Reform
     5. **An ‘Opt in’** approach has been endorsed – this applies to individuals, families and organisations
     6. Building **trusting relationships** is critical
     7. ‘Enabling Good Lives’ to build **on existing sector strengths**
     8. **Primary importance of the ‘personal planning process’ and the ‘facilitator role’**
  3. Concerns have been raised that “personal planning” and “independent facilitation” is not to be linked with current needs assessment functions, roles and practices. **There is a strong sense that the proposed ‘facilitator role’ needs to be allied with individuals and families.**
  4. Separating personal planning from assessment and the allocation of funding has been widely discussed.
  5. There is consensus that ‘facilitators’ need to be seen as independent but not necessarily a distinct organisation – there could be a variety of organisations, with different approaches, but achieving the same outcome (i.e. the ‘personal plan’) that could be used by a variety of funders.
  6. Many of the groups highlighted:
     1. Establishing **security of an appropriate level of funding** is vital
     2. There are obvious **links to a Whānau Ora approach**

1. **Challenges**
   1. Designing a plan for service/sector transformation when only some aspects of current funding/services are included but positive that MoH and MSD have shown commitment and leadership
   2. Managing increasing expectations – many contributors to the process are excited about Enabling Good Lives providing a framework for much wider sector transformation
   3. Some stakeholders feel we have been here before with other initiatives which have ultimately not followed through and therefore we need to do something different this time if we are to succeed. There is a sense that this ground-up process may provide the difference
   4. Some stakeholders suspect a ‘hidden agenda’. Key question: “Does ‘choice’ mean real choice i.e. Can I keep some existing services if I choose?”
   5. There is uncertainty regarding the links, if any, with other ‘Enabling Good Lives’ projects. There is the strong desire for a framework that connects various initiatives currently being undertaken by Ministry of Health, Ministry of Social Development and Ministry of Education i.e. common principles and strategic links
2. **The “bottom line” and “ideal” perceptions associated with service and sector transformation**

**Family/Whānau Forum**

|  |  |
| --- | --- |
| **“Bottom Line”** | **“Ideal”** |
| People are safe | Individuals are valued for their contribution to the community |
| Supports and services must vary from person to person | Flexible use of funding |
| Services are not eroded i.e. valued services remain | Increase real participation in the community |
| We don’t lose anything | Disabled persons and families have more of a “real” voice – control over funding and resources |
| No-one is worse off | Good services are strengthened – and able to expand |
| There is a holistic approach taken – whole of life | People are not “led” – independent advocacy and a variety of communication approaches |
| Specialist services remain – the viability of current specialist services is not threatened | There is an “ombudsman/independent authority that families can approach |
| Any change will enhance quality of life | People are able to make real choices – these may change over time and the “system’ will enable this |
| Choices are real – and different choices will be respected | There are clear accountability processes |
| There are continued “open forums” to discuss changes | We all live in a more valuing community |
| It must be a staged process – learn as we go | “Facilitators” must have a real experience of disability issues – qualifications are not enough |
| All political parties must agree – or change is vulnerable | Growth must be organic – based on an individual’s journey and not imposed |
| Individuals are meaningfully occupied in ways that enrich them | People can have more options with services and in the community |
| There is a national database created – ability to plan | There are increased connections within the community |
| Start early (from birth) with independent facilitator role | The community is more aware and educated |
| People are not just tolerated – but accepted in the community |  |

**Service Provider Forum**

|  |  |
| --- | --- |
| **Bottom Line** | **Ideal** |
| EGL needs to be from birth, encompassing all life stages | Reduce stress for individuals and family |
| Holistic approach to child and family. | Create strong families – competent self-advocating families |
| Focus on health, safety, belonging and contribution. | Optimize intervention services |
| Set up a hub system approach to services (one stop shop) | Local services would welcome people – “additional resource may be required” |
| Accessibility to all the local services (generic community services) | Lead advocate service is available by choice, with dignity as a their priority |
| Individual funding on all levels – to purchase services of own choice | Support options outside of box |
| Right people, right skills, right support | Strong competent educated and well remunerated support staff |
| That a person is not worse off and more disadvantaged then they already are. | Freedom of access to all services and activities |
| Enhancing and adding choices without taking away what is already existing | Personal growth for everyone |
| A persons funding is not open to potential abuse (strong safeguards put into place) | Recognition of current funding inadequacies |
| The disabled person must be driving the plan making | To get rid of the label/term “disabled” |
| Need a well-skilled personnel to deliver the service of the disabled person | Try to keep it simple |
| A quality plan will equal a good funding outcome.  Services will still be there - viable | Strengthen natural networks – peers |
| Everyone able to access equitable (based on need) funding to meet desired outcomes, as in facilitated plan | Backups for people/families/external networks, e.g. loss of employment placement. Safety mechanisms to immediately access facilitation when things change |
| In 5 years time, everyone is better off, living in the community and have a positive difference in their lives. | Holistic approach between service streams, attitudinal changes. |
|  | Person-directed approach. |
|  | Full and meaningful life with real choice |
|  | Greater opportunities for being part of the greater community |
|  | More funding |
|  | Enhanced community (both with their peers and wider communities) |
|  | Facilitation role key |

1. **Success Criteria**
   1. Disabled persons are supported to positively contribute to community life evidenced by:
      1. Supports and services that are customised and build on the strengths and aspirations of the individual
      2. Improving access to mainstream opportunities that enable people to have a good life
   2. Families are supported to enable their disabled child to get the most out of life:
      1. Accessible information at an early stage and at key transition points
      2. Ability to influence the design of aspirational plans
   3. Government can evidence its commitment to the United Nations Convention on the Rights of Persons with Disabilities:
      1. Creating the conditions for disabled persons and their families/whānau to have more choice and control over their lives
      2. Enabling Ministries to work collaboratively across traditional boundaries
      3. Advocating for the rights of disabled persons and their families/whānau to be able to access mainstream opportunities in order to have a good life
      4. By being itself less visible in or central to people’s lives

**Appendix 16: Key Messages from Written Submissions**

“... endorse the recognition of the importance of the need for systemic changes in order to bring about the meaningful and sustained transformation that is sought and are encouraged that this is being considered alongside the Christchurch project processes and actions.”

“It is vital that EGL and the various New Model initiatives are better connected. There should be an overarching framework with the same underpinning principles”

“Strongly support the principle of ‘whole of life’ support being designed around the person rather than trying to ‘make the person’ fit the criteria for a certain type of support.”

“… potential in the proposals for duplication in planning and facilitation that is already happening (for example some organizations have people working in community connector or outcome facilitator roles) or is being tried out as in the “new model” with local area coordination (LAC). Integration and clarification are needed so *that everyone is working on the same page*.”

“Timatanga – (beginning early) totally agree, need to move away from ‘entitlement thinking’, families need to be ‘strengthened’ early, this requires skilled people to ‘work alongside’ the person and their family”.

“Critical questions to be addressed include - how will the functions of NASCs, DIASs and the new model initiatives fit together and what changes are necessary so they do and the system is made simpler?”

“The EGL project must:

* Allow providers and people to ‘opt’ in at the point that best suits them.
* Respect people’s need for familiarity, safety and stability.

Ensure that change management processes do not go at a pace that adds more stress”

“...endorses the cross government integrated funding approach that is taken in the EGL report and the emphasis on there being flexibility and a range of options rather than people having to fit into what is available”

“Ministry of Education (MoE) must be at the table with MSD and MOH”

“Strongly support the principle of ‘whole of life’ support being designed around the person rather than trying to ‘make the person’ fit the criteria for a certain type of support.”

“Reassurance is needed that hard fought for gains and agreements will not be lost such as VHNORS funding from school/education transferring to MSD for post school options and that the commitments made at the time of deinstitutionalization concerning day supports”

“The EGL plan needs to reflect the reality that for many disabled people, particularly people with intellectual disabilities, the community is not a welcoming or inclusive place. It will take time and a concerted, intentional effort by a range of government and community agencies to change this.”

“Government agencies, including TEC and Work and Income, need to consider how they can make ‘mainstream’ services accessible”.

“ … current service specifications are urgently reviewed to ensure they are flexible so providers can be innovative …”

“We support an approach which is based on clear principles and allows services to develop their own plan in accordance with the circumstances of their service users and community”.

“Disabled people and families need to be able to access support to understand and manage IF and will need further information and assistance about the implications of IF and portable funding in the context of the EGL project.”

“We are concerned about statements from Ministry officials about internal discussions they are having about whether change should be incremental or ‘big bang’. This implies a lack of understanding about sustainable change processes, which require the buy-in and commitment of all stakeholders. International research clearly shows that externally imposed change is the least successful method of affecting sustainable change, and that ‘scapegoating’ or making people (in this case, providers) feel they are the problem only leads to resistance. A partnership approach between disabled people, families, providers and government, with everyone understanding their respective roles and responsibilities, is required if we are to achieve the goal of Enabling Good Lives.”

“Particular consideration needs to be given to those who people who do not have active family involvement in their lives in developing and/or strengthening people’s natural support networks”.

“Safeguards need to be in place for those situations where families or others in caregiver/supporter roles are acting in ways that are not in accord with the best interests or wishes of the individual concerned”.

“The value of parent networks should be recognized”

“The discussion regarding Enabling Good Lives is still focusing on ‘high level’ matters. It is essential that people have the chance to understand the principles and concepts and so these conversations are important and should not be hurried. We are, however, concerned about the timeframe for the project when we are one month out from submitting a plan and there is still very little detail available and we are unsure what EGL will look like in practice. We believe that the timeframe is too tight, and that it is more important to get the plan right than it is to work to politically imposed deadlines”.

“Simplify processes for family/whānau to avoid overwhelming information that confuses or intimidates”

“MSD need to consider some kind of funding allocation for each person, the MOH already have an Individualised Funding model, MSD could ‘link’ into this. If people do not want to manage their own funds then MSD could contract with current MOH contracted disability providers who with authority from MOH could combine the funding to provide ‘holistic’ support. Government should look at the concept of individual budgets for people who access government funded services via multiple government services. This cuts down on the governments costs in administering multiple funding streams for one person and saves the individual from the experience of multiple review systems, as well as providing the individual maximum flexibility around how the disability, health, social and education funding for which they are eligible is used”

“It is difficult to see how individualised/portable funding will be worked out from existing funding. We cannot endorse any new system until we have seen how this will happen and what the likely implications are”

“Strengthening Family/Whānau - We consider this element of EGL needs strengthening to reflect a wider family systems perspective that is also more in tune with the principle of *kotahitanga tatou – whānaungatanga* that is espoused with supports based around relationships and unified partnership. The starting point should be one of respecting families, seeing families as allies and building trusted relationships and connections. This does not mean ignoring and not addressing situations where there are tensions but building solid relationships provides a sound base for those times when difficult conversations need to be had”

“Families have seen positive changes in day services that have followed changes introduced as a result of *Pathways to Inclusion*. These have included greater individual choice, a wider array of activities that their family member is engaged with and increased community participation. They do not want to see a reduction in the quality of support from that currently experienced.”

“Providers will need transition support as they will be working in several ways as this is rolled out. They will need support for training and bridging, as they will have old and new contracts running at the same time. The EGL project should explore what is needed in this regard to move from one system to another”

“Self-determination – tino rangitiratanga: Access to independent advocacy is key to achieving genuine self-determination. Independent Advocacy should be offered (and funded) by default to anyone without family member, friend or other independent person”.

“Provider organisations need some certainty of funding in order to be economically viable. This needs to be considered when developing a mechanism for individualised/portable funding”.

“Funders need to establish better relationships and communication between a wider range of people who can all contribute to the development of service specifications that move from a “one size fits all” model to arrangements that are responsive to individual service and support designs, are outcome focused and allow for future flexibility for changing needs and aspirations”.

“Families have expressed a wish to have access to a ‘navigator’ type role very early in the life of a disabled child. We agree that this would be optimum. Unfortunately part of the system issues for families with a child born with an intellectual disability or autism is that there is a lack of appropriate services to navigate them to. These issues are not going to be solved within existing funding”.

“Mannaakitanga – community building, feel that the best way to create ‘community’ is for people to actually be present, participate and contribute; currently people do not have the support they need to take part in their community”.

“Services will need to develop new processes to administer individualised budgets. This will require investment for most organisations, and will also require additional administrative resource. This was frequently raised as an issue by both services and government officials in Victoria when we visited in December to learn more about their transition to self-directed approaches. In Victoria the state government recognised the need for a budget management system and designed and implemented one for services. Services have found the system onerous and said they under-estimated the extra administrative infrastructure they would need to both individualise budgets and to provide accountability reports to service users on a monthly basis. Services in NZ are already under considerable financial pressure with most having to do more with less”.

“Already families face difficulties with the supports currently available, for example when young people transition from school and available funding limits the days and times they can access day supports. We know of situations where parents, have not been not able to take up work or have had to give up work as a consequence of the shortfall in funded support.”

“Flexibility in contracting so people do not have to fit a certain box before they can get the support they need”

“Funders need to establish better relationships and communication between a wider range of people who can all contribute to the development of service specifications that move from a “one size fits all” model to arrangements that are responsive to individual service and support designs, are outcome focused and allow for future flexibility for changing needs and aspirations”.

**Comments Specific to Personal Planning and the “Facilitator Role”**

“…We also urge that there is only be one plan for an individual so that everyone involved has a shared understanding and is working to the same plan”

“More thought needs to be given to the link between planning and implementation. Our experience of successful personal planning has shown that:

* A good life looks different for every person, and everybody has different circumstances
* Most people need to experience decision-making and the opportunities available to them so that they can make informed choices.
* Personal planning works best when it is a process rather than an ‘event’. This involves on-going conversation with the person, observation of what is working or not working, and gaining an understanding of the person – especially when communication is a barrier. It is least effective when it is a detailed, periodically reviewed document”.

“Whatever planning and implementation process is adopted needs to provide flexibility and the opportunity for the person to change their mind”.

“Initiate the “self-held record” to cut down on the number of times people have to tell their story to different agencies. (Person controls how much of this they share with the people/organisations that come into their lives).”

“... provide simplicity, and not create another layer of bureaucracy and assessment for people who are currently able to access good planning and are fulfilling their goals ...”

“... Sufficient time for all clients to investigate all options. This time frame may vary from client to client.”

“Planning and facilitation approaches need to be respectful of people’s choices and situations. Some people may choose a ‘specialised place’ as their community. Centre based services need to remain as a choice and be respected as a legitimate choice”

“We respect and understand the need for independence in the planning process. We do not, however, agree that the only option for ensuring this occurs is to have an ‘independent’ facilitator undertake the planning process”

“Clients to be allocated a mentor/support person to access all information and choices possible. This person would also advocate accordingly ie a person overseeing the whole picture, and making adjustments where and when required. (With accountability).”

“Information that is accessible and support for decision making are crucial so that people can make informed choices. Sufficient time should be allowed to enable individuals with an intellectual disability to participate meaningfully”

“There are a number of agencies with staff working in roles and in ways that are consistent with what is proposed. If they are not the challenge is to help them change into the sort of services that do provide the ‘right’ help rather than create a new profession of ‘facilitators’.”

“ONE organisation to distribute the funding to services as the client instructs. This would limit the reduction of funding that the client is able to use because by having one organisation you are only paying one lot of administration costs”.

“Facilitation’ as a way of working with people is something that many community participation and day service providers have been thinking about and developing in their own organisations. There is a shared understanding, based on the Tuhana resource and the SAMS training, provided through the VASS administered Training Fund, that this is about being of service rather than providing a service”.

Clarify and distinguish between:

* The principle of working in a ‘facilitated’ way.
* Who does the planning
* Who implements the plan”

“Independence can be built into the process by making the ‘facilitator/planner’ accountable to the person (and his/her family), both in terms of results and budget allocation. If this is linked to external accountability to the funder, then it should eliminate fears of client capture, which is presumably what is behind the idea of an ‘independent’ facilitator.”