

Brackenridge
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Organisational Submission – Review of Adult Decision-Making Capacity Law

Introduction

Brackenridge is a registered charity that provides 24/7 accommodation and living support to children, young people and adults in Canterbury. We work in partnership with families to also provide short breaks away to support whānau resilience. At the core of our practice philosophy is our belief in all people and their right to live in and be part of their community, and to exercise citizenship.

History

For over 20 years, Brackenridge has provided high levels of disability support to people and their families, along with family resilience care and community mentoring to adults and rangatahi in Canterbury. Brackenridge was formed in 1999, following the closure of the Templeton Centre, to support 84 intellectually disabled people with complex support needs. A clustered housing environment comprised of 14 homes was built adjacent to the previous Templeton Centre site.

Brackenridge has evolved to remain relevant to people with disabilities and their whānau by developing greater individualisation in our responses, community networks and initiatives. We currently support 200 disabled people and their families. 150 people 24/7 through community residential services and a further 50 people with respite family resilience support. Our practice is outcomes focused and informed by the Enabling Good Lives vision and principles. We strive to challenge the status quo and advocate for change that better supports full equality and inclusion of all disabled people. Every day, we learn more from the people we support and their whānau, and this in turn leads us to be better at providing the support they want and need.

Collaboration & Partnership

As an organisation, we walk alongside people with intellectual disabilities, autism and complex support needs to support them and their whānau to achieve what they want in life. We work in partnership with people and their whānau to understand their aspirations, and then help to create their “My Life My Way” plan that identifies the outcomes they are seeking and the possibilities to make their dreams become reality.

The Brackenridge Whānau Group was established to help our organisation learn from the people who choose Brackenridge as their support provider and to collaborate to improve programmes, services, and policies. The group is a panel of family members and key carers of some of the people Brackenridge serve. Providing advice on how to best meet the needs of current and future service users, the group is instrumental in high-level decision-making, welfare and guardianship advice, along with advocacy matters. Several of the group members have provided their own submission on the law review.

QUESTION 1

Do you agree with the terms we propose to use in our review? If not, what changes should we make?

- a) Support
- b) Prefer 'Neurodiverse'
- c) Support
- d) Suggest 'Person experiencing distress'.
- e) And f) Support

QUESTION 2

Have we identified the tikanga principles and concepts most relevant to decision making? If not, what changes should we make?

We advocate for being guided by Te Ao Māori about this.

QUESTION 3

How is tikanga Māori relevant to you in relation to decision-making, and to affected decision-making?

It is important for our ability to be responsive to Māori.

QUESTION 4

In situations when someone's decision-making has been affected, have you and your whānau/hapū/iwi been able to act in accordance with tikanga Māori in the way you would want? If not, how could this be improved?

As per our response to Q2.

QUESTION 5

Do you agree with the seven guiding principles we have developed? If not, what changes should we make?

We would be guided by iwi/ hapu.

QUESTION 6

Has someone supported you to make a decision, or have you been a decision making supporter to someone with affected decision-making? If so, how well do you think that process worked? What could be improved?

While we have resisted taken on a legal decision-making role, we are involved in supporting a number of people who have orders in place. Brackenridge has a wide range of experiences supporting these people.

The quality of decision making is a result of the quality of the relationships between all of the parties involved. Where these relationships are strong and nurtured throughout the year we see decisions that, in our view are in the best interests of the person. Where the relationship is more intermittent, it can be difficult for the person appointed by the court to understand all of the aspects of the supported

person's life. As such, we would like to see more reference made to the quality of the relationships and how these are maintained over the years.

In general, we consider that many of the people who have orders in place could be assisted to make their own decisions and we would like to see guardianship rates reduce in our sector. We are not satisfied that the threshold is high enough to take away this very fundamental right. We also see it as stopping people developing the skills required to make decisions for themselves, and if there was a way to create a graduated process of withdrawal from the order that would aid in developing more independence.

QUESTION 7

Have you experienced making, or been involved in using, an advance directive? If so, how well did you think that process worked? What could be improved?

The advance directives we have had in place have come from family.

QUESTION 8

Have you made, or been involved in using, an enduring power of attorney? If so, how well did you think that process worked? What could be improved?

We have not been involved in this.

QUESTION 9

Have you been involved in a process of making decisions for someone else under a court order, or having decisions made for you under a court order? If so, how well did you think that process worked? What could be improved?

We have not been involved in this.

QUESTION 10

Do you think there should be more ways for other people to be involved, in a more collective way, in decision-making arrangements when a person's decision-making is affected? If so, how?

Yes. While this will be more challenging to achieve, it is valuable to have perspectives from the wider whānau and not just a next of kin.

For example, support staff who support an individual on a daily basis may have a different perspective from that of a family member who interacts with the individual on an infrequent basis. This is just like any other family where friends and natural supports may be in more regular contact than a formal next of kin.

QUESTION 11

Do you think there are any other decision-making arrangements we should explore? If so, what are they?

We think there is a lot of potential to examine consensus decision making models from Te Ao Māori and Pacific communities. While these approaches may not need to be codified in legislation they could be referenced and accounted for in legislation.

QUESTION 12

What things might make decision-making arrangements easier or more effective?

We think training to those involved would be useful. We also think one of the constraints that people are faced with is urgency. To support someone to make their own decision takes time and this is not always factored into the processes that organisations and systems develop.

QUESTION 13

Do you think there needs to be safeguards or accountability mechanisms when a person with affected decision-making has an informal decision-making supporter? If so, what should they be?

The system surrounding a person who needs support is often very risk averse and this impacts on a person developing decision making skills. They are often protected from the consequences of their decisions which removes an important component of learning.

We often account for the risks someone faces if they decide to do something, and it can be challenging to balance this with the missed opportunity associated with the person not trying something new (because 'we' consider the action too risky). This has the potential to lead to a limited life for the person because everyone is trying to keep them 100% safe.

We also have experience where, in our opinion, the well-intended whānau member, is making decisions that are not in a person's best interests and it can be difficult to navigate this with whānau. This type of scenario may need additional support from independent agencies to hear concerns before the matter needs to be taken challenged through a court which is always extremely difficult for us. Recent examples include decisions around whether a person we support in a shared living environment should receive a COVID vaccine.

QUESTION 14

Do you think there needs to be safeguards or accountability mechanisms when a person uses an enduring power of attorney? If so, what should they be?

Yes. Using more than one enduring power of attorney to hold each other accountable or ensuring key contacts and/or support providers have input on who should be the enduring power of attorney.

QUESTION 15

Do you think there needs to be safeguards or accountability mechanisms when a person moves to a rest home or care facility? If so, what should they be?

We do a lot of work on transitioning someone into service. However, the process is not independently monitored. The decision for someone to move into full time support needs to be carefully scrutinised, but those involved in the process are not independent. Once a person is being supported typically there are a range of accountability mechanisms in place (whānau involvement, audits, Health & Disability Commission etc.)

It would be good to consider whether these mechanisms are adequate or what the impact of any power imbalance with their service provider is. Increasing a person's ability to make decisions for themselves will assist them to hold their service provider accountable, and further consideration about what needs to happen if the person is unable to make decisions for themselves.

QUESTION 16

Do you think there needs to be safeguards or accountability mechanisms if a person has a welfare guardian? If so, what should they be?

Yes. Having key person and/or service provider input on who should be the Welfare Guardian. A review system put in place for when the term expires. We are not sure that we give sufficient weight to the fact that someone else has taken over another person's fundamental right.

We think guardianship should be reviewed more frequently, and the monitoring of the performance of the guardian should involve input from a multi-disciplinary team of people. There should be an ability to suspend guardianship quickly were there are concerns about the exercising of guardianship, the default position should be that no-one needs guardianship and if we put it in place, it is rare and regularly reviewed.

QUESTION 17

Do you think there needs to be safeguards or accountability mechanisms to help supporters? If so, what should they be?

For employees, we run an OCP (Occupational Counselling Programme), or we have supervision for staff dealing with intense services. We think these should be offered to supporters. They are making life decisions for an individual therefore a level of training should be mandatory, however there is a need for ongoing processes of support and accountability. We think a supervision model would deliver this.

QUESTION 18

Is there anything else you would like to tell us?

We engaged with the families of people we support for their input and experiences into this law. We had two families respond with their experience. Both family members asked for their input to be included in our organisational submission.

Please see the two experiences below.

Experience 1 - Foster parent of a young person we support – Not named but recorded as A.

A(foster parent) talked about how he is getting older (77 years) and the substitute decision making responsibility has been handled by a support worker who has grown to know his foster son since 2014. This substitute arrangement is not lawfully recognised. A is not recognised as the Power of attorney. B'(the disabled person) s foster mum passed away from brain cancer, and since that time A has been making decisions about B's financials, medical care, and future supports.

The support worker is not employed with Brackenridge anymore, however because of the longstanding close relationship that was formed, the support worker was happy to continue to support B one on one. Funding this situation is provided via EGL flexible disability supports.

Experience 2 - Foster parent of a young person we support.

The thing is one size does not fit everyone. Over my time as POA and Guardian I am happy with how it goes and works for me and C. The level of accountability is good with having to put everything into the courts yearly and Public Trust auditing regularly. My only bug bear is its difficult to be able to make investments. The responsible thing for C is to have a POA guardianship order. It is the POA's responsibly

to make sure C is provided for in his lifetime, investment opportunities would be helpful in that regard. My other bug bear is not being able to do a will on C's behalf, it requires that he signs it, and I won't agree to C putting a cross on any legal document. It's my responsibility as POA to make sure C is to make sure these things are done responsibly and in C's best interest.

So in a nut shell one size doesn't fit all. For some people POA etc isn't needed as long as accountability is there, I have no concerns with how it's working.

QUESTION 19

How easily could you access information about the review and how to make a submission? What could we do better?

More information and discussion through established networks.

QUESTION 20

How easy did you find making a submission? What could we do better?

Good. Maintain information flow via established networks.