



Joint Submission of IHC and Idea Services about the Law Commission's Review of Adult Decision-Making Capacity Law Preliminary Issues Paper

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1. Key message

The importance of adults being able to make their own decisions, and receive appropriate support to do so, cannot be understated. A person's dignity is severely undermined by substitute decision making, their safety can be compromised, as well as their ability to respond to and navigate unsafe situations. New Zealand must hasten its path to embedding effective and appropriate supported decision-making and ending historic substitute decision-making frameworks.

2. About IHC

IHC advocates for the rights, inclusion, and welfare of all people with intellectual disabilities and supports them to live satisfying lives in the community.

IHC was founded in 1949 by a group of parents who wanted equal treatment from the education, health, and social service systems for their children with intellectual disability. Today IHC is still striving for these same outcomes and is committed to advocating for the rights, welfare, and inclusion of all people with an intellectual disability throughout their lives.

We believe that people with an intellectual disability have the right to be to be part of a family, to be treated with respect and dignity, to have a say in their own lives, to live, learn, work and enjoy life as part of the community, and to have support that meets their goals and aspirations.

IHC is New Zealand's largest provider of services to people with intellectual disabilities and their families via our subsidiary, IDEA Services. IHC supports 1500 families with children who have an intellectual disability, provides support and training for 4000 adults in workplaces and helps more than 3500 people with disabilities to live in IHC houses and flats. We also provide specialist services such as behaviour support and training.

IHC advocates for the rights of all people in New Zealand with an intellectual disability (estimated population 89,000 NZ Census Disability Survey 2013).

3. Questions from the Preliminary Issues Paper

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

The term Learning Disability is contested. We are aware that People First and overseas organisations such as Mencap use it, however, IHC finds that it can include people with dyslexia and these individuals frequently do not have similar life experiences as people with intellectual disability. IHC prefers to use the term intellectual disability.

The term 'affected decision-making' is vague terminology, for example people who have consumed a lot of alcohol may have affected decision-making. A possible alternative is 'people who need decision-making support'.

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

Yes, these tikanga principles are relevant to decision-making. Connecting these principles to decision-making in practice may require further explanation and IHC would appreciate the opportunity to provide further comment on this aspect.

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

The principles do not discuss ensuring that appropriate support is accessible— this is a key part of decision-making for people with affected

decision-making. One of the huge gaps in the current system is support for people who do not have family or friends to help them make decisions.

Similarly, the principle recognising and facilitating relationships on trust – appears to assume that family or whānau need to be or will be involved. For many intellectually disabled people there are no friends, family, or whānau available for involvement and this needs to be recognised. For many intellectually disabled people in residential care only their support staff are able to support them to make decisions. This is not ideal and can be difficult for the service provider and its staff.

We have been contacted many times from various service providers about what is available for people in these situations as staff are concerned that there is no one with a long-term non-professional relationship available for this person. This is a huge gap in the current system, and it urgently needs addressing.

The idea of distributional equity is not included – the idea that those who experience disadvantage in access to decision-making support should be prioritised. IHC would argue that laws and policies about adult decision-making affect intellectually disabled people disproportionately, and for the longest amount of time, so consideration of the needs of intellectually disabled people should be prioritised when reforming the related law.

The principles must commit to moving from substitute decision-making to supported decision-making. This is a part of the Convention, and the Committee on the Rights of Persons with Disabilities has again raised concerns about New Zealand's lack of progress in abolishing the guardianship system and substituted decision-making regime and replacing that regime with supported decision-making systems.

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?

IHC is involved on a regular basis in processes regarding Court orders and decision making. We have many case studies that we could share, both from a general advocacy and service provider basis.

One recent example involved supporting an individual in Disability Supported Living who wanted to challenge a Welfare Guardianship application. This man had a historic Welfare Guardianship arrangement in place with little examination of whether this was in fact needed, and without his specific input, and he had gone on to live a very independent life. However, because of the Court arrangements, the man was unable to access his own funds to support his challenge in this case (because of a Court-appointed Property Manager limiting his access) – for example to secure a proper capacity assessment, rather than the tick box form and basic GP assessment that was provided to the court to continue his Welfare Guardianship. His Welfare Guardian (and Property Manager) lived in another country and was unavailable at times for consultation as well as being someone that the man did not get along with. The man's repeated requests to the appointed lawyer for the subject person to challenge or oppose the Welfare Guardianship application went unheeded. IHC then loaned the man money to pay for a proper capacity assessment, as he was unable to access his own money, which showed the man had capacity in many areas. This in turn allowed him to hire his own lawyer to oppose the Welfare Guardianship application, ensure that he was able to participate in the Court process, and regain legal control of his life. There were failures at all levels of the system in this case and it was difficult, costly, and time consuming to challenge the Court process and ensure that this individual had his voice heard.

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, there are many models of collective decision making such as circles of support or microboards. It is important to be aware that intellectually disabled people may have had less opportunity to meet other people, join social groups, or build and sustain relationships and so are unlikely to be able to create and manage circles of support on their own.

It is also important to consider a disability service provider's role in this process, especially where the individual may be supported in residential care on a 24/7 basis. IHC will be keen to engage further about this during the review process.

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

Instead of substitute decision-making arrangements it could be worthwhile to investigate representative agreements. These agreements are where a person formally authorises a third party to act on their behalf. The person making the agreements retains the ability to revoke the agreement and must be consulted about decisions. Usually, the representatives talk to the person who made the agreement on a daily basis. The co-decision-making process could also be investigated.

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?

Yes, there must be safeguards and accountability mechanisms for informal decision-making support. These can include age requirements (supporters must be over 18 for example), vetting, and training for people who seek to provide decision-making support, reporting requirements for how property and assets are managed, as well as a body that can accept reports of possible harm and investigate them.

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?

Similar safeguards to the above. Concerns about enduring power of attorneys can currently be made to the Family Court, however, there needs to be consideration about whether approaching the Family Court for intervention is easy or reasonable, especially in time-sensitive circumstances. A specialist tribunal or government body might be a more approachable option.

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?

Yes, there needs to be a community visitors scheme for rest homes and care facilities. There also needs to be an adult safeguarding service that is available for reporting issues of concern.

From a service provider perspective, it is important to ensure at the beginning of providing care that there is an appropriate understanding of someone's capacity and ability to make decisions about their daily life. It would be useful if there was a best practice or consistent approach in regards to this overall situation in future.

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

There are additional safeguards needed before it is decided that a person needs a welfare guardian if New Zealand is to continue with substitute decision-making. Capacity assessments must be more thorough than a tick box, they need to consider the different types of capacity that people may have, and they must be completed by people that have the time and the knowledge to properly assess the capacity of an adult in their particular circumstances.

Welfare guardians need mandatory training on what being a welfare guardian entails and about human rights and involving the subject person in all decisions. They also should be advised of their responsibility to be in contact with the subject person of the guardianship frequently (preferably every week).

Welfare guardianship must be reviewed properly every three years and there should be a rebuttable presumption that the welfare guardianship will be dissolved at every review. Importantly, the subject person should always be involved in an application process, and should have an opportunity to have their say, unless there is a clear reason why not.

People under Welfare Guardianship also need a system in place where they can challenge their Welfare Guardianship without needing access to large sums of money.

IHC has previously lobbied for an Office of the Public Advocate similar to the model used in the Australian state of Victoria. IHC would like to see the establishment of a Public Advocate backed by an independent statutory body that advocates for adults who need decision making assistance,

mediates disputes about adults with decision making needs, investigates situations of potential abuse, neglect, and exploitation of adults who are at risk of harm. This is a significant gap in New Zealand, and it needs to be addressed by a properly funded national system.

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

Paid disability support staff often feel exposed when they are the only people assisting an intellectually disabled person with decision-making. Free independent supporters should be available to provide to assist to paid support staff who are helping an intellectually disabled person make decisions.

Medical professionals also feel similarly out of depth when making decisions about another person's capacity. In an article published in the New Zealand Medical Journal titled 'What do doctors know about assessing decision making capacity?' it was found that there was a significant lack of confidence amongst doctors regarding their ability to do capacity assessments that would be presentable to a court. Most doctors did not use a structured method of assessment and a significant number of them did not think that making capacity assessments were within their scope of practice even though assessing a patient's capacity is an integral step to obtaining consent for any medical treatment and therefore a critical part of all healthcare. **(Young, Douglass, & Davison, 2018)**

From a service provider perspective, we often find that many individuals who we support do not have any obvious supporters available – for example no family or friends available to assist. This is an area needing further consideration in future in terms of who can be available from a public setting to act in a support role.

Is there anything else you would like to tell us?

Intellectually disabled people are the people who are most likely to suffer due to a perceived lack of decision-making ability. This affects them from birth until the end of life, unlike other groups who may only find this to be an issue after an accident, illness or a certain age. This means that intellectually disabled people should be co-leading all the work related to affected decision-making support.

Cognition and capacity are only one part of making a decision, motivation, emotion, personal experiences of the decision maker and situational context are all a part of decision making as is the personal experience of the decision maker. For intellectually disabled people, it is crucial to consider their personal experience.

Some intellectually disabled people may have never been given the opportunity to make even minor decisions about their lives and so may need significant levels of support in order to gradually have the experience that most individuals have. This doesn't mean that they should not be given this support in order to get this experience regardless of how expensive or difficult it may be.

Intellectually disabled people are also more likely to be isolated and have only their parents and immediate family to rely on for decision-making support. Any informal decision-making systems they may have in place can become destabilised or disappear as parents age and pass away. Intellectually disabled people may then have to set up new systems of decision-making support, often at a time of heightened vulnerability (a parent's death may mean they must change their entire lifestyle).

IHC was surprised to see in the section of the Preliminary Issues Paper section 7.32, about substitute decision making, a paragraph about how it is

difficult to make sure that only in the most extreme cases substitute decision making is used, especially when it is cheaper and quicker to appoint a substitute decision maker to decide rather than support the person to make their own decision.

The importance of adults being able to make their own decisions, and receive appropriate support to do so, cannot be understated. A person's dignity is severely undermined by substitute decision making, their safety can be compromised, as well as their ability to respond to and navigate unsafe situations.

Canadian disability rights advocate Michael Bach has declared guardianship to be “[s]tate-sanctioned removal of personhood from an individual with respect to one or more or all areas of personal decision-making.” **(Bach, 2006)** It has also been characterised as a ‘civil death’. **(Perlin, 2013)**

Cheapness or quickness cannot be weighed against the diminished personhood that occurs as a result of substitute decision making. IHC recommended that the reviewers read the recent Donald Beasley Institute report, *‘Tell me about you: A life story approach to understanding disabled people’s experiences in care (1950-1999)’*. This report demonstrates very clearly how the removal (or the non-development) of decision-making power has disastrous consequences for intellectually disabled people.

Whilst IHC wants to see substitute decision making regimes ended, the current Protection of Personal and Property Rights Act 1988 takes the appropriate stance in assuming that everyone is presumed to have capacity, however IHC finds that this understanding is not borne out in practice. It is critical that any new decision-making regime has significant resources about capacity, decision making and human rights training for medical and legal professionals as well as ongoing support for them when navigating this area.

In the Paper there was discussion given to accessing of personal information of people with affected decision-making. An example of Hemi's mother contacting a bank to gain banking information is given. Any intellectually disabled person can have an account mandate that sets out who is entitled to information about the account. It is important to balance the concerns of family and whānau with the privacy rights of the individual, especially considering that very few submissions from intellectually disabled people will be made to review committees.

IHC would also like to see greater effort expended to include non-verbal and high and complex needs people in consultation for this review. The consultation process should also ensure the accessibility of information, for example, the use of Easy Read. This would enable many people with an intellectual disability to participate in the consultation process.

Thank you for the opportunity to comment on the preliminary issues paper. IHC is keen to continuing engaging with the review process and we believe we are in a unique position to offer case studies and other relevant details. We look forward to further engagement and wish you well with this important work.

Works Cited

- Bach, M. (2006). Legal Capacity, Personhood and Supported Decision Making. *Canadian Association for Community Living*.
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