

# Does it matter?

Decision-making by people  
with learning disabilities

July 2017



**People First**  
(Scotland)



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## FOREWORD

As chairperson of People First (Scotland) I am delighted to present this report.

People First has campaigned for positive change in the lives of people with an intellectual impairment (learning disability) in Scotland for more than 27 years.



We are the only disabled person's user-led organisation of people with learning disabilities in Scotland and the organisation is run by and for its members. I am proud to say that I am a founding member of People First.

Over the years, People First in Scotland has grown into a national network of local self-advocacy groups whose members and democratically elected area representatives direct this Disabled People's Organisation genuinely and meaningfully. We recruit and select our development workers who offer support in the decisions that we make on the Board and in our local groups.

The issue of decision-making being denied to people with learning disabilities has always been around for us. In our Citizens' Grand Jury report in 2011, we called for guardianship to be reviewed and replaced with a system where our own autonomy over our own lives could be recognised. We have occasionally lost members from our Board of Directors who have been placed under guardianship orders when we know they are capable of not only making decisions in their own lives but in our national organisation.

Our Law and Human Rights Group, with funding from Comic Relief, has been campaigning for laws in Scotland to recognise the citizenship of people with learning disabilities in Scotland and for us to have the same human rights as other people.

We believe, from our own experience, that the typical experience of a person with learning disabilities in regards to decision-making is quite different from other sections of the community. Many people with learning disabilities will transition from childhood to adulthood and find they have no more control over their lives than when they were children. Informally, families will often make practical decisions and arrangements for living and support services may do the same when families are not available.

More formally, guardianship orders and intervention orders tend not to be awarded because the person with learning disabilities has lost capacity to manage their own affairs (unlike other groups) but simply in recognition of impaired intellectual capacity which has always existed. The trigger for such formal intervention can be anything from the person making an unwise decision to being vulnerable to harm or to being non-compliant with informal substitute decision-making. Increasingly, in Scotland, families are being encouraged to seek powers of guardianship before the person reaches the age of adulthood.

In some of our discussions, it has been suggested by professionals, by lawyers and by medical practitioners that not only do people with learning disabilities lack the capacity to make their own decisions but they are quite content to have decisions made on their behalf.

We applied for and were awarded funding by DRILL – Disability Research into Independent Living and Learning to conduct a research project led by disabled people. We are the first project to complete under the DRILL programme in Scotland.

We asked the question:

*‘Can supported decision-making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision-making?’*

and very particularly:

*‘Does it matter to people with learning disabilities whether they are supported in their autonomous decision-making or have substitute decision-makers in their lives?’*

Our Law and Human Rights Group brought together a steering group to oversee and direct the project. The steering group designed, agreed and revised the questions, developed the approach, trained members to act as peer researchers and conducted the research project in partnership with Animate Consulting.

A pilot group of members, unconnected to the steering group assisted the process, offering their time to develop, consider and improve the accessibility of the research and the materials used in it.

The steering and pilot groups developed accessible materials which explained the process, ensured that participants knew what they were agreeing to do, knew they could stop at any time and knew that the report would not identify them.

People First was not surprised that this research concluded overwhelmingly that the answer to our main question was 'yes'; making decisions does matter very much to people with learning disabilities, as it does to any other citizen.

Our report will tell you more about this and the other further questions that we asked. I hope that you find the report interesting and that you take the learning from our research with you.

Fiona Wallace  
Chairperson, People First (Scotland)

#### Comments from the research steering group members:

*'This kind of research makes people think differently about us. People can see that we have a voice.'*

*'Peer researchers got the opportunity to learn interview skills. They used questions we had designed so we knew that they would work.'*

*'People had a voice. They were heard. It was a 'safe space' for people because they knew that anything they said was anonymous and they would not get in trouble for anything I said. I reminded people who took part in interviews and focus groups all the time that there was no right or wrong answer and that no one would judge them for what they said. They could answer anyway they wanted.'*

*'I feel the research opened the eyes of people with learning disabilities about their human rights. Most people did not think that making decisions about their life was a human right. We also learnt that some people had never thought about how much choice they actually have in their life until they took part in the research. What they used to think was choice, was in fact not a real choice.'*

*Some of us did not know what research was before we started. Many people did not know what decision-making was. The research has been a way for a lot of people to learn more and understand different things.'*

## EXECUTIVE SUMMARY

In Scotland, more than 1,000 people who have a learning disability have some, or all, of their right to make decisions removed through a guardianship order each year. Whether the process of substituting their decision making with the decisions of a court appointee can be avoided by facilitating supported decision making has become an international debate.

The debate was prompted by Article 12 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), and the subsequent General Comment by the convention's committee. The 'Cheshire West' English court ruling has further focussed attention on issues of consent and deprivation of liberty in the UK.

### The research project

In October 2016, People First (Scotland), in partnership with Animate Consulting, was awarded Disability Research on Independent Living and Learning (DRILL) funding to research substitute and supported decision making in Scotland. The core research question was:

Can supported decision making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision making?

The supplementary questions the research sought to answer were:

1. Does it matter to people with learning disabilities whether they are supported in their autonomous decision making or have substitute decision makers in their lives?
2. Would substitute decision making still be needed for some people or for some kinds of decisions?
3. How might the 'decision-making supporters' be defined, authorised and monitored?

128 people who have a learning disability were interviewed about their experiences of decision making by researchers who themselves have a learning disability. In addition, international literature on the subject was reviewed, and a small number of stakeholder interviews conducted.



## The legal context

The relevant Scottish legislation is the Adults with Incapacity (Scotland) Act 2000. This enables, where someone is found by a court to lack capacity, a guardian to be appointed to make decisions over their financial and property, or welfare, matters.

At a UK level, the UK Parliament's Human Rights Act, and the European Convention on Human Rights on which it is based, don't specifically reference legal capacity. At an international level, unlike the European Convention on Human Rights, the UNCRPD has not been embedded within UK or Scottish legislation.

## Peer research findings

In the main, participants described making decisions by themselves in a very positive light. It made them feel happy, good, powerful, proud, excited, in-control and independent. They felt that making decisions for themselves was important; having choice and freedom to be independent was strongly emphasised.

A small minority reported that they generally didn't make decisions for themselves, with decisions being made by support staff or their parents, for example. They did what they were told to do, even if they wanted to do something different. Others reported that making their own decisions was sometimes difficult and stressful.

Participants reported getting help with making decisions from a wide range of people and organisations, including family members, partners, friends, support staff/key workers, advocacy workers and financial guardians. These people helped with, amongst other things, reading letters, managing money and welfare benefits, and choosing a new place to live.

Participants generally reported being supported to make decisions as a positive experience. It worked best for those that could get support if they needed it, who knew the 'supporter' well, had built a relationship with them and trusted them, and were genuinely listened to. In these situations, it felt good, reassuring and calming.

Some participants reported that they sometimes found it annoying or overwhelming when supported, and that prevented them from making decisions. Most reported that they found it hard to say no. This was mainly because they were concerned or afraid of upsetting people. Others said that when they do say no they are not listened to, or that they say yes when they would rather say no because there might be comeback.

Participants reported that they commonly experienced decisions being made about them without people asking them. The majority had been told they were *not allowed* to make some decisions, and some had been told that they were *not able* to make some choices or decisions.

They attributed these situations to a wide range of people, including family members, carers, support staff, social workers and financial guardians. The decisions affected included changing and cancelling support, what people should wear, what time they could come and go, what to do each day and how to manage money.

These situations made participants feel a range of negative emotions including controlled, powerless, upset, angry, frustrated, confused, not valued, left out, lonely, worried, worthless, helpless and unfairly treated. Some, however, accepted a decision made on their behalf if they saw it to be a good one that they agreed with.

Good practice examples were identified relating to choosing independence, choosing a staff team, support as the accused in court and deciding about personal relationships. These are included in section 5, with further, more detailed, case studies in appendix 2.

### **Decision making challenges facing people who have a learning disability**

Substitute decision making occurs across a range of decisions, not just the most significant. One of the reasons for this is the continuing view of adults who have a learning disability as children. Another is the power imbalance that exists between people who have a learning disability and those they engage with in society.

The link, within the Adults with Incapacity (Scotland) Act 2000, of decision making ability with ‘mental disorder’ undermines the chance of people who have a learning disability obtaining the support they need. A continuing desire to protect them, and a focus on their mental capacity rather than their ability to make a decision, limits their ability to make the decisions that are right for them.

### **The current guardianship system**

None of the 1,098 applications in 2015-16 for guardianship relating to someone who has a learning disability were unsuccessful. Applicants and the state face significant legal costs, whilst courts are gridlocked due to the number of applications. The rules for gaining Legal Aid for legal costs may actually be encouraging welfare guardianship applications. There is certainly a failure to adopt the Adult with Incapacity Act’s



second principle of taking the least restrictive approach; Legal Aid funding may be exacerbating this issue too.

Whilst the Act's third principle is the need to take account of the wishes and feelings of the person seen to lack capacity, many decisions appear to be made on the basis of a person's 'best interests' instead. It would seem that the fifth principle, relating to developing the person's decision-making skills, is being overlooked, given the large proportion of guardianship applications for young adults. There also appears to be a failure to give weight to the will and preferences of a person seen to lack capacity.

The Act does not provide for a situation where support for decision making could enable someone to understand an issue, and make, their own decisions. The perception of guardianship as the 'gold standard' by financial institutions, in particular, is seen to undermine supported decision making and encourage guardianship applications.

Monitoring guardianships effectively presents a significant resource problem for the regulatory bodies. Whilst they attempt to tackle the worst behaviour by guardians, those subject to guardianship have no mechanism for rejecting their guardian and apparently little hope of challenging poor decision making made on their behalf.

### **Practical challenges in delivering supported decision making**

Good supported decision-making requires the person offering support to delve deeper to understand the true basis for decisions, rather than a simple stated preference. They must also understand, and remain aware of, what comprises good and bad practice in doing so.

In cases where it is hard or impossible to clarify what a person's will or preference may be, the concept of 'best interpretation' is promoted. Ensuring such an interpretation is not actually a decision in the person's 'best interest', is challenging.

The risk of undue influence by a decision making supporter is recognised; the current system is seen to have legal 'checks and balances' despite its failings. Supported decision making does provide an opportunity to move away from a situation where a single person or body, the guardian, decides on behalf of someone. This could, however, present a challenge in terms of both finding sufficient supporters, when resources are short, and monitoring them for undue influence.

## Progress in the introduction of supported decision making

Across the world, advances are being made in the introduction of supported decision making, but no jurisdiction has yet eradicated substitute decision making. There is little consistency in the terminology used for, or level of capacity required to appoint, someone who supports with decision making. Whilst certain core elements of their role can be identified, the decisions that they can provide support with differ.

People can also be empowered to make their own decisions by relaxing the requirement, in terms of capacity, required by someone to make a legally-enforceable decision. Ireland's Assisted Decision-Making (Capacity) Act 2015 is a good example of where capacity is measured on a 'functional' basis, for specific decisions, rather than the previous 'status' basis where someone was judged to have, or not have, capacity.

## Conclusions

Can supported decision-making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision-making? The evidence suggests it can in most, if not all, cases – but only with a significant change in mindset as to rights, resources and risks involved.

It really does matter to people who have a learning disability that they can make autonomous decisions. When people make their own decisions it makes them happy, and they feel valued and in control of their lives, and enabled to play a fuller part in wider society. The opportunity to seek the views, ideas, opinions and advice of trusted people in coming to a decision is highly appreciated.

Whether substitute decision making is still needed for some people, or for some kinds of decisions, is more challenging to answer; no jurisdiction has yet successfully eradicated substitute decision making. The answer as to how 'decision-making supporters' should be defined, authorised and monitored is also hard to answer, but Ireland offers some pointers. The more holistic approach in Sweden, which has been evaluated well in terms of its effectiveness, is also worthy of further research.

## 1. INTRODUCTION

Over time, significant changes have occurred in society's attitudes to people who have a learning disability. In the UK, they have mostly been released from incarceration in hospital wards and are generally accepted as having a place and a role in society. Their right to have a home, employment, education and relationships have been recognised in anti-discrimination and national human rights legislation.

However, the right for a person who has a learning disability to make decisions in relation to these fundamentally important areas of their lives continues to be restricted. This can happen when family or friends make relatively simple, day to day decisions, in an informal way for someone. Families may also feel compelled by professionals, or their experience with statutory services, to take formal control over some or all of their relative's decision making through legal action.

In Scotland, more than 1,000 people who have a learning disability have some or all of their right to make decisions removed by the courts each year. This has raised concern both amongst disabled people's organisations and the regulatory bodies set up to oversee these legal processes.

The Scottish legislation upon which such court actions are based addresses issues such as fluctuating decision making capacity through mental ill health, reducing capacity resulting from dementia, and permanent loss of capacity through brain injury. Whilst these situations could be seen to arise from a 'mental disorder', as the law terms it, there is growing recognition that the term, and the legislation based on it, is not relevant to, or meeting the needs of, people who have a learning disability.

In recent years there has been significant consideration at an international level of the law around decision making capacity. Whilst it would be good to say that the experiences of those who have had their rights infringed had led to this current discussion, it isn't necessarily so.

Instead, the catalyst was the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD), specifically Article 12 on equal recognition before the law. The subsequent General Comment 1 by the Committee on the Rights of Persons with Disabilities prompted particularly strong debate. Could, as the General

Comment insisted, substitute decision making really be replaced entirely by supported decision making?

The case of P v Cheshire West and Cheshire Council in 2014, involving of a person who has a learning disability and who lacks capacity, has further added to the legal debate. Whilst the core question was whether the person had been deprived of their liberty, one of the three essential elements in answering this question was whether the person has lacked the ability to give valid consent<sup>1</sup>. Could supported decision making play a part in resolving the issue of consent that is at the heart of this matter?

Disability Research on Independent Living and Learning (DRILL) funding has enabled us to return the focus onto disabled people's wishes and feelings. With DRILL being the world's first major research programme led by disabled people, it is appropriate that both the interviewers and interviewees in this research were people who have a learning disability. Their findings have been given context through a literature review and a small number of stakeholder interviews conducted by the report authors.

This report is not intended to further the debate on the UNCRPD and the General Comment; many others have already written eloquently on this issue. Instead, its focus is the views of people who have a learning disability, and on amplifying their views within the current debate about the need to revise Scotland's incapacity legislation.

## 2. METHODOLOGY

### 2.1 The questions we sought to answer

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The core research question was:

Can supported decision-making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision-making?

The supplementary questions the research sought to answer were:

4. Does it matter to people with learning disabilities whether they are supported in their autonomous decision-making or have substitute decision-makers in their lives?
5. Would substitute decision-making still be needed for some people or for some kinds of decisions?
6. How might the 'decision-making supporters' be defined, authorised and monitored?

### 2.2 Our research approach

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There were three strands to the research:

#### 1. Interviews with people who have a learning disability

Peer researchers, who have learning disabilities themselves, used a participatory/ Appreciative Enquiry approach to:

1. Gather the opinions and experiences of adults with learning disabilities in Scotland in relation to decision-making
2. Record examples of good practice in supported decision-making in areas key to independent living such as housing, relationships, justice, money, etc.
3. Develop a definition for supported decision-making appropriate to the Scottish context
4. Draw conclusions and recommendations as to how supported decision-making can be designed to replace substitute decision-making

The research was carried out by peer researchers, who have learning disabilities themselves, supported by People First workers using a participatory and appreciative approach. It was flexibly designed to enable formative learning and adjustment based on the implementation experience.

The peer researchers were recruited by People First and took part in an initial training workshop run by the project partners, alongside People First development workers. This gave the research teams the opportunity to learn about the research and the roles we were asking them to take up, and to practice working together using the prototype questionnaire that had been designed and approved by the project steering group.

### ***Sampling***

We aimed to consult 100 people with learning disabilities across Scotland using focus groups and individual interviews. We used a non-probability sampling approach known as purposive sampling, where we set out to identify and consult as wide a range of people that met the necessary characteristics i.e. adults with a learning disability, as we reasonably could within the constraints of time and budget. We were able to draw on People First's network of contacts to invite people to take part. It is important to note that it is not possible to draw statistical inferences from this kind of sampling method since, with a purposive non-random sample, the number of people interviewed is less important than the criteria used to select them.

### ***Ethics***

Easy read invitations and documents explaining the purpose of the research were issued through workers known to people in the various standing and specially formed focus groups. These documents included participant consent forms which explained that participants could choose not to answer any or some of the questions, and to withdraw from the research process without sanction at any point.

Participants were also informed that no personal information about them would be stored and that the information gathered from the focus groups and individual interviews would be anonymised both in note and report form. This was made clear to Peer researchers and the workers supporting them in the training and review sessions.



## **Review Session**

A review session involving the peer research teams and the project partners, was held after a small number of focus groups had been undertaken to look at how well the process and questionnaire were working, and the range and quality of information being captured. This led to a revised, shortened questionnaire incorporating greater use of prompt questions to help the peer researchers to 'dig deeper' into and explore participants experience. This was used in the subsequent focus groups and individual interviews to greater effect. A further revision and refocusing of the later in the process enabled the peer researchers to collect examples of 'good supported decision making'.

This research process enabled us to consult a total of 128 adults with learning disabilities across Scotland, through 21 focus groups and 19 follow up interviews with participants who wanted/needed more time to share their experience in more depth, and to collect a range of vignettes and 3 fuller case studies of good supported decision making.

## **2. Literature research**

Journals, position papers and policy responses from across the world were reviewed for relevant findings and practical experiences on substitute and supported decision-making.

## **3. Stakeholder interviews**

One to one, semi-structured, interviews were performed with the following specialists in policy and practice relating to incapacity in Scotland:

- Shaben Begum MBE, Director, Scottish Independent Advocacy Alliance
- Colin Fraser, Mental Health Officer, Glasgow City Council
- Brenda Garrard, PAMIS Self-Directed Support Lead
- Sandra McDonald, Public Guardian, Scotland
- Colin McKay, Chief Executive, Mental Welfare Commission for Scotland
- Adrian Ward, Consultant to TC Young LLP, specialist in incapacity law

In addition, meetings to discuss supported and substitute decision making, held by People First Scotland with the following specialists in policy and practice, were attended:

- Kirsty McGrath, Head of Policy – Reform of Adults with Incapacity, Scottish Government & Peter Quigley - Policy advisor, adults with incapacity review, Scottish Courts (seconded to Scottish Government)
- Jill Stavert, Professor of Law, Edinburgh Napier University

### 2.3 Issues outwith the scope of this work

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The primary focus of this report is longer-term measures to facilitate general decision making for those who have never had it.

The focus on longer-term measures means the report doesn't specifically cover Intervention Orders facilitated by the Adults with Incapacity (Scotland) Act 2000.

The focus on general decision making and legal capacity, rather than decision making in specific circumstances, means we have consciously not addressed decision making in relation to:

- compulsory treatment / deprivation of liberty under the Mental Health (Care and Treatment) (Scotland) Act 2003 (as amended)
- support and protection for adults viewed as vulnerable, as addressed through the Adult Support and Protection (Scotland) Act 2007

The report's focus is on people who have a learning disability, but the conclusions we draw are likely to be relevant to other people who may lack decision making capacity, including those with dementia, mental ill health or brain injuries.

Such people may also be able to utilise a Power of Attorney. Currently it seems unlikely, however, that such an approach would be seen as legally enforceable for people who have a learning disability. This is because their learning disability appears likely to preclude them from being seen as capable of assigning decision-making powers to another. Further research in this area would be beneficial.

## 3. BACKGROUND

Decision making by adults who have a learning disability is addressed at three levels: a Scottish level, a UK level and an international level.

### 3.1 Scottish level - Adults with Incapacity (Scotland) Act 2000

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The Scottish legislative approach to addressing the needs of those who lack capacity is defined in the Adults with Incapacity (Scotland) Act 2000<sup>2</sup>. This act defines 'incapacity' as being where a person aged sixteen or over is incapable of:

- '(a) acting; or
  - (b) making decisions; or
  - (c) communicating decisions; or
  - (d) understanding decisions; or
  - (e) retaining the memory of decisions,
- ...by reason of mental disorder or of inability to communicate because of physical disability'<sup>3</sup>

A person who falls into this category solely due to their inability to communicate is not judged as lacking capacity if their inability to communicate can be addressed by human or mechanical means.

Where someone is assessed as being incapable of making decisions, the courts can make a guardianship order<sup>4</sup>. This can involve property and financial matters (financial guardian), or personal welfare (welfare guardian), which can include health. Applications for financial and welfare guardianships can be made at the same time, and can request varying degrees of powers.

The applicant is likely to be an individual, such as a family member or friend; these are termed private guardians. The Act allows for the person seen as lacking legal capacity also to apply<sup>5</sup>, but their lack of capacity would seem to make such an application unlikely. A local authority can also apply if they believe the person is incapable of making decisions and no-one else has made or is likely to make an application<sup>6</sup>. This is termed a local authority guardianship.

An application for guardianship is made to the sheriff court. Two medical reports and a report from a mental health officer (in the case of a welfare application) or financial professional (in the case of a financial application) must be provided. The application is measured against two criteria; whether the person is incapable of exercising decision-making capacity and whether the guardian is suitable.

### Criteria 1: Is the person an ‘incapable’ adult?

The Act explains that the sheriff must be satisfied that:

‘(a) the adult is incapable in relation to decisions about, or of acting to safeguard or promote his interests in, his property, financial affairs or personal welfare, and is likely to continue to be so incapable; and

(b) no other means provided by or under (the Act) would be sufficient to enable the adult’s interests in his property, financial affairs or personal welfare to be safeguarded or promoted’<sup>7</sup>

### Criteria 2: Is the potential guardian suitable?

A sheriff should only appoint a guardian who understands the person’s circumstances and condition, and the needs arising from these. In addition, the applicant for guardianship should also understand the functions of a guardian<sup>8</sup>.

The following factors should be assessed by the sheriff in deciding someone’s suitability (highlighting in bold by the authors):

‘(a) the **accessibility** of the individual to the adult and to his primary carer;

(b) the **ability** of the individual to carry out the functions of guardian;

(c) any likely **conflict of interest** between the adult and the individual;

(d) any **undue concentration of power** which is likely to arise in the individual over the adult;

(e) any **adverse effects** which the appointment of the individual would have on the interests of the adult;

(f) such other matters as appear to (*the sheriff*) to be appropriate’<sup>9</sup>.

## The Act's principles

The Act requires the following five principles<sup>10</sup> to be applied when deciding which measure will be most suitable for meeting the needs of someone who is considered to lack capacity. They must also be used whenever actions or decisions are made on the person's behalf<sup>11</sup>. Any action or decision must:

1. Benefit the person, and be necessary
2. Be the one that restricts a person's freedom as little as possible
3. Take account of the present and past wishes and feelings of the person
4. Be made in consultation with relevant others, including the person's primary carer, nearest relative, named person, attorney or guardian (if there is one).

In addition, any guardian (or other person given powers under the Act) must:

5. Encourage the adult to exercise whatever skills he has concerning his property, financial affairs or personal welfare, as the case may be, and to develop new such skills.

## 3.2 UK level - Human Rights Act 1998

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The Human Rights Act incorporated the European Convention on Human Rights into the UK's legislation. Judges must read and give effect to other laws in a way which is compatible with Convention rights, and it is unlawful for a public authority to act in a way which is incompatible with a Convention right<sup>12</sup>.

The European Convention on Human Rights, and the Human Rights Act, don't specifically reference legal capacity. However, depriving someone of their right to family life (Article 8), or liberty (Article 5), has significant implications in this regard<sup>13</sup>.

## 3.3 International level - United Nations Convention on the Rights of Persons with Disabilities

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The UK, rather than Scotland, is the signatory to international treaties and is therefore the state party to the UN Convention on the Rights of Persons with Disabilities (UNCRPD) and its Optional Protocol.

Unlike the European Convention on Human Rights, the UNCRPD has not been embedded within UK or Scottish legislation. It is possible to prevent devolved Scottish legislation and actions of the Scottish Government where they are believed to be incompatible with the UK's UNCRPD obligations but this is at the discretion of the UK government<sup>14</sup>

However, the Scottish Government has signalled its respect for the Convention with its 'Delivery Plan, A Fairer Scotland for Disabled People'. It sees this plan as being part of its work 'to meet our international obligations under the UNCRPD'<sup>15</sup>. Two actions are particularly relevant to this report:

- **Action 15:** We will work with disabled people and the organisations that represent them to develop changes to the Adults with Incapacity Act...to assess compliance with UNCRPD by 2018.
- **Action 16:** We will review policies on guardianship and consider circumstances in which supported decision making can be promoted.

## Article 12 – Equal recognition before the law

Article 12 requires that states who are party to the UNCRPD:

'shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life'

Support must be given to disabled people in exercising legal capacity. Appropriate, effective and proportionate safeguards to prevent abuse in relation to the exercising of capacity are required, which should:

- 'ensure that measures relating to the exercise of legal capacity respect the rights, will and preferences of the person
- are free of conflict of interest and undue influence
- are proportional and tailored to the person's circumstances
- apply for the shortest time possible, and
- are subject to regular review by a competent, independent and impartial authority or judicial body'



## UNCRPD Committee: General Comment No.1

Following significant discussion and stakeholder engagement, the UNCRPD Committee issued a General Comment in 2014 which provided clarity on the rights and obligations contained within Article 12<sup>16</sup>. It reiterated its previous statements that State parties to the UNCRPD must:

‘review the laws allowing for guardianship...and take action to develop laws and policies to replace regimes of substitute decision-making by supported decision-making, which respects the person’s autonomy, will and preferences’<sup>17</sup>

It defined substitute decision-making systems as existing where:

- ‘(i) legal capacity is removed from a person, even if this is in respect of a single decision;
- (ii) a substitute decision-maker can be appointed by someone other than the person concerned, and this can be done against his or her will; and
- (iii) any decision made by a substitute decision-maker is based on what is believed to be in the objective “best interests” of the person concerned, as opposed to being based on the person’s own will and preferences.’<sup>18</sup>

The Committee outlined key provisions that are required in a system of supported decision making if they are to be compliant with Article 12 of the Convention<sup>19</sup>.

These can be summarised as:

- (a) The system of supported decision making must be available to all, regardless of the level of support someone needs
- (b) Decisions must be based on the will and preference of the person, not on what is perceived as being in his or her objective best interests
- (c) A person’s communication impairment must not be a barrier to obtaining support in decision-making
- (d) States must facilitate the creation of such support and ensure it is legally recognised and accessible. Third parties must be able to verify those providing support and challenge their actions

(e) Affordability should not affect access to support with the exercise of legal capacity; support should be available at nominal or no cost

(f) Someone's need for support in decision-making must not be used to justify curtailing other fundamental rights such as the right to vote, the right to marry and found a family, and the right to liberty.

(g) The person must have the right to refuse support and terminate or change the support relationship at any time

(h) Safeguards that ensure a person's will and preferences are respected must be set up for all processes relating to legal capacity and support in exercising legal capacity

(i) The provision of support to exercise legal capacity should not hinge on mental capacity assessments; new, non-discriminatory indicators of support needs are required in the provision of support to exercise legal capacity

## 4. PEER RESEARCH - FINDINGS

The peer research group conducted 21 focus groups across Scotland (detailed in Appendix 1), involving 128 people. 19 follow up interviews were performed with people who wanted more time to share their experience in more depth.

The findings are organised under 3 key decision areas:

1. Decisions you make by yourself without support or help from anyone
2. Decisions that people help you to make
3. Decisions people make about you without asking you

### 4.1 Decisions you make by yourself without support or help from anyone

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In the main, participants talked about making day to day decisions themselves without help and support from others. These included decisions and choices that shaped their daily routines, for example: when to get up, what to wear and eat, when to do housework, when and where to go, what kind of activities to undertake, and where to go on holiday. People often referred to making plans around their budgets.

*"I make decisions that make me happy!"*

*"it empowers me to speak up, speak my mind."*

*"I always plan my decisions around my budget to make it easier."*

*I feel it's better if I decide where I spend my money. If somebody else does my shopping, they might get something I don't want or don't like.*

*They also included making decisions and choices about work, where to live, support and relationships: who to be friends with, who visits me, whether to have a boyfriend or not, whether to have a pet, what kind of work/volunteering to do, where to go for support and changing support times.*

*"I made the decision to volunteer to help children with diabetes. It is important that they get the right support and medication. This is based on my own experience."*

*"I think you should try to make your own decisions. When you live in a flat staying with other people, sometimes it's difficult to do things how you want them. You've got to tell your staff what you want. Now I've got my own flat. It's good to make choices of your own."*

*"I chose to dump my boyfriend. He said he wanted to get married and he lied."*

When asked how they went about making choices and decisions, participants talked about thinking about and weighing up what they wanted to do, the needs that they have, asking for advice and listening to others, deciding then planning what to do and putting it into action.

*"I like to get help but only if I need it."*

*"I like to study my care plan and choose – this is very important."*

A small minority reported that they generally don't make decisions for themselves, for example, decisions being made by support staff, that their mum and dad make the decisions and that that they do what they are told even if they want to do something different.

*"Sometimes I don't decide. the workers decide. They don't ask and help me – they tell me what I am doing. Sometimes I want something different and they say no."*

*"I don't really decide – mum and dad decide."*

*"It is very difficult for me to make decisions because of where I stay. I live in a shared house with others and the care staff don't listen and they question my decisions."*

When we asked how they felt about making choices and decisions by themselves, we received a mixed response. In the main, participants described making choices and decisions by themselves in a very positive light - it made them feel: happy, good, powerful, proud, excited, in-control and independent.

Participants felt that making decisions for themselves was important. Having choice and freedom to be independent was strongly emphasised. It was important to 'be your own boss', to affirm and reinforce for yourself that you can do things, and keep some things in your life private. It was essential to be listened to, so people don't

control your life or bully you into doing things you don't want to do. They also talked about how, in doing this, it was important to feel listened to and trusted.

*"You should make decisions for yourself and not let other people do them. If you say yes to other people, you might not be happy."*

*"Yes, because then I feel I am being listened to and that I am part of the world and society. We shouldn't be discriminated against."*

*"Sometimes it takes me a while to make up my mind but I feel good once I've done it."*

*"I feel it's learning; to do it yourself. You learn to do things for yourself and that is important."*

*"When people make decisions for you, you feel powerless ... you feel like a child. You are not being allowed to grow up."*

Others reported that making their own choices and decisions was sometimes difficult and stressful - that it made them feel nervous and scared, that they needed time to think and sometimes 'just had to do it'.

*"It depends on my mental health – sometimes I find it stressful to make my own decisions"*

*"Sometimes I have gone against what my parents tell me to do – sometimes I say no. I get nervous and it upsets me but sometimes I feel angry."*

*"I don't feel good about myself – I feel bad. It's all inside me – I feel trapped because I can't make my own decisions. People don't listen – it feels good to get this out just now."*

*"I can't make decisions at home because of my situation (guardianship)"*

*"I feel nervous when I've got to decide things (choices) for myself but I still do it. It makes me feel good to still go ahead with it."*

*"Sometimes it's hard because I need time to think about things and to choose what I want to do."*

## 4.2 Decisions that people help you to make

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We asked about people's experience of being helped and supported to make choices and decisions. Participants reported that they get help from a wide range of people and organisations, including: family members, partners, friends, support staff/key workers, advocacy workers, financial guardians, advocacy groups, social workers, Neighbourhood Networks, People First, Local Area Coordinators, job coaches and benefits advisors.

The kind of choices and decisions participants reported being helped and supported to make included: advice and support with reading (letters), managing money (budgeting and the benefits system), shopping for clothes and household appliances (help with sizes and which cooker to buy), help choosing a new place to live (what support I would need/get), finding information on the internet, holidays, filling in forms, medication and GP appointments, important phone calls and talking to people, and attending reviews.

*"They make suggestions and bring ideas – I chose what I want and tell them what I want."*

*"I phone my mum and talk things through with her."*

*"I ask them. "Do you think I should do this?", and I make a choice at the end."*

*"I get support when I go to the doctor – so I have help to understand the information."*

*"My advocacy group helped me to decide to move in together with a friend."*

*"My mum and dad helped me when I decided to move out of my house. They said it was up to me. They helped me move out. I talked to them. They were supporting. They helped me in getting a flat. They helped me and gave me advice. They were speaking to me and reassuring me. They came with me to the flat viewings."*

When we asked participants how they felt about being helped and supported to making choices and decisions, they generally described a positive experience. It worked best for people where they could get help and support if they needed it, and they knew the 'supporter' well, had built a relationship with them and trusted them



and were genuinely listened to. In these situations, it felt good, reassuring and calming.

People found it helpful to have support for bigger decisions, and for double checking intended decisions, to sit and talk and share ideas.

*“The good support workers listen to me and then help. I have some support workers who help and some who don’t. The ones who listen help. They explain things. They take time. They ask me questions.”*

*“I feel it is quite good because if somebody that knows you and you trust them, they can give you good advice.”*

*“I find it helpful because they might come up with something I’ve not thought about. I’ll start thinking about it and might do it. I know I’m getting the right advice. It comes down to trust – who you can trust.”*

*“If I’m doing something, I need all the information to make my choice. Other people can help me get the information and make sure it is accessible to me.”*

*“I need to do some things for myself but sometimes it’s difficult with choices that involved a lot of things. Sometimes I know what choice I want to make but I double-check with other people I trust.”*

*“Sometimes I make the wrong decisions. Sometimes I make mistakes. It is a good thing to have someone help you out.”*

*“Sometimes you have to compromise – come to a solution together, not just one person deciding on their own.”*

Some participants reported that it wasn’t always good and that they sometimes found it annoying or overwhelming, and that prevented them from making decisions.

*“Sometimes I feel pressurised into making a decision that suits other people.”*

*“It’s all very well somebody helping you but at the end of the day it’s your decision.”*

When asked if they ever say ‘no’ to help and support with making choices and decisions we got a mixed response. Most participants reported that they found it hard to say no. This was mainly because they were concerned or afraid of upsetting

people. Others said that when they do say no they are not listened to, or that they say yes when they would rather say no because there might be comeback.

*"It is hard to say no to a family member."*

*"I find it really hard to say no, it can be easier to keep quiet."*

*"(It) would be harder if there wasn't someone there to explain the consequences of the decision."*

*"I can't say no to them – I have a guardianship."*

Some reported that they were confident to say no, and that this depended on the relationship. For example, it was easier to say no to a friend than a parent, and that if they didn't know the person they would be much less likely to trust them and more likely to say no.

*"(I say no) when I was choosing staff and my mum helped me"*

*"(I say no) all the time but it doesn't mean I'm listened to."*

*"I say no when staff tell me to go to bed."*

*"I find it quite easy. I say thanks but no thanks."*

*"Easy. I used to find it hard. I've been coming here (advocacy organisation) for a while and I've grown better at speaking up for myself."*

And a few said they never said no.

*"It can be hard to say no to a workers' help. I never did. I was scared I'd be sent to the office or sent home or something."*

*"You need people to help you in your life. I just let my parents help me out. I never say no."*

*"I don't bother, not really. I'm scared they will jump down my throat"*

### 4.3 Decisions people make about you without asking you

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Participants reported that they commonly experienced decisions being made about them without asking them, and attributed this to a wide range of people, including: family members, carers, support staff, community support workers, social workers and financial guardians.

*“All the time. I don’t get much chance to decide anything. I get decisions made for me and I don’t like it. I’m 47 years old not 12. I want to be able to decide what I do and where I go.”*

The decisions made without asking people were wide ranging, and included: changing and cancelling support, what people should wear, what time they could come and go, what to do each day - where they will go and what they will do (activities), what medication to take, how to manage money and where they can go on holiday.

This made participants feel a range of negative emotions: controlled, powerless, upset, angry, frustrated, confused, not valued/devalued, left out, lonely, worried and terrible.

*“Makes me feel low because I like to be independent.”*

*“The bank moved money from one account to another without asking me.”*

*“Some people don’t get a choice when to leave the night club. Support staff decide when to leave, when their shifts are finished.”*

*“It makes you feel as if your choice has been taken out of your control. It does not make you independent either. It kind of makes you feel like you are treated like a child, not like an adult.”*

*“I feel angry – the reason is because they never consult with me when decisions are being made. They make decisions they think are right for me but they never ask.”*

*“Often decisions have been made before they even speak to you.”*

We asked if participants had been told they were **not able** to make some choices or decisions and how that makes them feel. We received a mixed response, some saying they had experienced this while others had not.

*“Before I lived where I do now. I was told that all the time, but things have changed and are much better now.”*

*“Someone said to me ‘You will never be able to work or have your own flat’. I have proved them wrong.”*

*“I am on Option 3 of Self-Directed Support. I wanted to go on Direct Payments. I wanted to employ my own staff. I had a couple of people I wanted as Personal Assistants. The Council wouldn’t let me do it. They said I couldn’t sort money out. I felt heartbroken.”*

*“I have a girlfriend I want to be closer and spend more time with her but my family won’t allow this. They control when I see her, and where, and how much time I speak with her on the phone. Sometimes my dad just takes the phone off me when I’m in the middle of talking to her. He says I’m on the phone too long with her.”*

The majority of participants who had experienced being told they were not able to make some decisions described how that made them feel in negative terms: angry, upset, hurt, frustrated, and ashamed. They generally felt they would have made a different decision to the one made for them.

Others accepted a decision made on their behalf if they saw it to be a good one that they agreed with.

*“(I was) cross, annoyed at the time. But glad now because my health has benefited from it.”*

We similarly asked if they had been told they were **not allowed** to make some choices or decisions and how that make them feel. The majority of participants reported that this had been their experience.

*“Yes. I wanted to visit the mother of a friend of mine who had passed away. I wanted to visit her in the evening and she said she would welcome a visit anytime and that she would like to see me. But staff at my accommodation said I wasn’t allowed to go. That was it. I was very angry and frustrated. If I*

*had been allowed to make the choice myself I would have gone to visit her. I know exactly what bus to take and I usually sit close to the driver.”*

*‘Sometimes in houses (residential units) when they are short staffed the residents are told they can’t go out because there is no staff available to support them.’*

*“I have been told (by the support service) that I am not allowed to make any more complaints. I feel upset and hurt. I feel like my rights are being taken away.”*

The experience had left them feeling: annoyed, angry, confused, disappointed, ‘skint’ (money), frustrated, worthless, helpless, a lack of confidence and unfairly treated.

*“It makes me feel unhappy, upset, vulnerable - like life is not really your own.”*

*“Yes. I would fight for my rights now... I would travel on my own now.”*

Some reported that they would have made a different decision to one made for them.

*“Yes – going to the bank. I’m not allowed to take my card with me. This is unacceptable and, yes I would have made a different decision.”*

*“Everyone can make mistakes – we should get the chance to learn from our mistakes.”*

The examples participants gave of decisions they were told they were not able and/or allowed to make included: health matters, sexual relationships, learning to drive, travelling independently, what time to return to their residence, where to live, visiting their partner’s house on their own.

## 5. PEER RESEARCH - GOOD PRACTICE EXAMPLES OF SUPPORTED DECISION MAKING

During the peer research, we were able to collect and further explore examples of good supported decision-making processes.

Four vignettes drawn from the peer interviews with people who have a learning disability are presented below. Three additional, fuller, case studies are included in Appendix 2.

### 5.1 Choosing independence

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*“I used to hate it (being supported to make choices and decisions) – I was stubborn. Because I was getting older (18), I wanted to feel older.*

*Before I lived on my own I fought for my independence; I wouldn’t ask for help. I wanted my family to see that I could live on my own.*

*My mum was worried about me getting my own house. She was worried I would not manage and that I would be taken advantage of or bullied.*

*I was desperate to get my own house so we had to work it through. We talked about things but I know she struggled with it. She realises now that I can do my own thing and that I will get help when I need it.”*

### 5.2 Choosing my staff team

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*“I get involved in choosing my own staff. I do this with support from a worker from my support organisation, interviewing, asking about new staffing. It’s important to do that.*

*They ask me ‘How do you feel about new staff starting?’ and ‘would you be interested in helping get the new staff in?’*

*Now we are going on to have sleepover staff and we need new staff to come work at the house. It is very important to get new staff. We don’t have enough.*



*The worker is in the meeting with me. She asks me what staff I'd like and how I would like to describe that for the application. I need help to make those choices. It would be very hard if she was not there. She puts the application online. She prints out the completed applications and I can see them. They help me read them.*

*In the interview, I sit in and ask them questions. I ask them 'why would you like to work here?' I get to ask them if they would be confident to work here. Later they ask me 'who do you want to choose?' I was pleased about the new staff we hired."*

### 5.3 Support as the accused in court

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*"I had to appear in court as the accused. I had no idea of the process. Better to get a lawyer, the lawyer would know better about how the system works. If I tried to do it myself, I'd be lost.*

*The lawyer helped me decide how the best way to plead in court was. Also, she helped me make a decision about how I wanted to put my case to the court, what was the best way of defending myself.*

*She was honest, clear in the way she spoke and she explained things in a way I could understand. She explained what would happen. If there were any words I was unfamiliar with, she would clarify what that meant. She also put in a lot of effort to make me feel as comfortable as I possibly could. She consulted with me before she recommended any special measures like getting to have somebody to support me in the court. I took her legal guidance. It was reassuring.*

*She helped me decide what to say when presenting my case. She helped me choose the wording of what I was going to say. We looked at the questions in advance and thought about what I was going to say. She helped me make the decision about how to put it across.*

*I think what was really helpful was knowing the possible scenarios / options. When I was deciding what to plead, we went through each option and she explained what would happen if I decided this one or that one, what the outcome would be. The options were guilty, not guilty and no plea. I said what I thought and then she said what she thought and then we agreed what the best would be. We discussed the options.*

*When it came to the actual trial, she made sure that special measures were put in place, breaks and a supporter sitting beside me. The supporter was there to explain/clarify anything to help me understand. I was happy enough with the decisions I made with their help.”*

## 5.4 Deciding about personal relationships

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*“I wanted to have a boyfriend. I met my boyfriend on Facebook. I met him in Dundee for the first time. I spoke to my mum and my sister before I met him. They told me to be careful.*

*I listened to that advice and really appreciated it. We have been going out for nearly 3 years now. My family have met him and like him. I am pleased with my decision and the support I got. I now have a flat, a boyfriend, and a pet”*

## 6. CHALLENGES FACING PEOPLE WHO HAVE A LEARNING DISABILITY IN RELATION TO DECISION MAKING

The peer research, literature review and stakeholder interviews suggest a range of issues stand in the way of people who have a learning disability taking greater control of their decision making.

### 6.1 Substitute decision making occurs across a range of decisions, not just significant decisions

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The peer research suggests people who have a learning disability are likely to experience challenges in relation to decision making on a daily basis. They are likely to find difficulty in exercising their right to autonomy in tasks as simple as choosing where to go and who to see, as well as in complicated tasks such as buying a house.

### 6.2 Many people who have a learning disability continue to be seen as children

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It is argued that a shift towards supported decision making sends a symbolic message regarding the rejection of avoidable paternalism<sup>20</sup>. Paternalism in decision making extends to the view of people who have a learning disability as ‘forever’ children, as many of the participants highlighted. People who have a learning disability and who are over 16 are adults in the eyes of the law and should be seen that way.<sup>21</sup>

### 6.3 A power imbalance exists between people who have a learning disability and those they engage with

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Power imbalances exist in relation to professionals and their clients or patients, such as those in the health field, regardless of the existence of any impairment<sup>22</sup>. It would seem likely that this is exacerbated when such professionals are addressing the needs of those with a learning disability.

Participants in this research highlighted a power imbalance in relation to many of those they engage with, including their families and support staff. It is reported that people who have a learning disability may be unaware of their right to reject such a

situation because information is not available for them in a format that they can understand<sup>23</sup>.

Such a power imbalance can lead to undue influence being exerted over someone who has a learning disability. The vast majority of those assisting people who have a learning disability in relation to decision making are, however, unlikely to exercise undue, and malevolent, influence<sup>24</sup> of the like reported by the Mental Welfare Commission in 2012<sup>25</sup>.

However, it is likely that those unskilled in supporting decision making are likely to affect how decisions are made, even if they do not intend to do so. This may well extend to substituting their decision for that of the person who has a learning disability in relation to particular issues.

Recently published research, learning from trials in Australia, highlights that ‘building the knowledge and skills of family members/friends (natural supporters) is one of the most effective ways to support and sustain the decision-making ability of the person with disability.’<sup>26</sup>

#### **6.4 The term ‘mental disorder’ remains linked with learning disability**

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The Adults with Incapacity (Scotland) Act 2000 links the need for assistance in decision making with people who have a ‘mental disorder’. It is recognised that people with a learning disability are not mentally ill; learning disability is a lifelong condition, which cannot be cured or treated by medication<sup>27</sup>.

The continuing reference to a mental disorder is opposed by some people with learning disabilities, and their organisations<sup>28</sup>. Continuing this link risks undermining attempts by people who have a learning disability to obtain the support they need to make decisions.

#### **6.5 Many factors affect the success of support in decision making, other than a person’s capacity**

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There are simple steps that people who provide support with decision making can take to ensure they keep the rights, will and preference of those they support at the centre of their decision making<sup>29</sup>. A range of resources have also been made

available by the Scottish Government, Mental Welfare Commission and Office of the Public Guardian.

Those who have a role supporting someone with decisions (whether informally or formally through a guardianship) do not, however, need to demonstrate any specific competency or qualification to do so. A lack of skills, time pressures, different values bases, access to communication supports and the relationship with the person needing support all have the potential to impact on someone's success in supporting decision making.

## 6.6 The need to protect should not outweigh the dignity and autonomy of someone who has a learning disability

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Laws relating to incapacity should balance the rights of people to exercise their legal capacity, with their protection in situations where it would not be acceptable to hold them responsible. The European Court of Human Rights recently noted that:

‘The Court is mindful of the need for the domestic authorities to reach, in each particular case, a balance between the respect for the dignity and self-determination of the individual and the need to protect the individual and safeguard his or her interests, especially under circumstances where his or her individual qualities or situation place the person in a particularly vulnerable position.’<sup>30</sup>

The balance differs between countries in the UK in relation to contract law. In Scots law, a contract apparently entered into by a person lacking sufficient capacity is not valid or legally binding, regardless of whether the other party was aware of the incapacity<sup>31</sup>. In England, it would be a valid contract but the other party could choose to cancel it.

This attempt to balance enabling and protecting is not limited to people who lack capacity. Stakeholder interviewees recognised that we all require support with making decisions at times, be that from a financial adviser, car mechanic or lawyer. In addition, the state may choose to substitute certain decisions that individuals would otherwise make. For example, the state, through the Unfair Contract Terms Act 1977, does not allow people to sign up to contract terms that are unfair.

It would appear from the evidence of the research participants, however, that the perceived need to protect outweighs the right to make decisions for many people who have a learning disability.

## 6.7 There remains a focus on mental capacity, rather than on the ability to make decisions

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Someone's capacity to make decisions is no longer determined in law solely by their diagnosis or impairment. There remains, however, a focus on the mental capacity of individuals, rather than on their ability to make decisions about certain issues in certain circumstances<sup>32</sup>.

Such an approach does not reflect peoples differing abilities at different times or in different areas of their lives. It would also suggest that people's right to change their minds, or make seemingly 'wrong' decisions, are curtailed.



## 7. CHALLENGES WITH THE CURRENT GUARDIANSHIP SYSTEM

### 7.1 A lack of rigour in the granting of guardianships

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In 2015-16, 1,098 welfare guardianships were awarded for people who have a learning disability. Approaching half of these (504) were for someone aged 16 – 24. The Mental Welfare Commission believes this situation may arise from the introduction of Self-Directed Support<sup>33</sup>.

The Mental Welfare Commission also suggests that guardianships should be granted on a time-limited basis, especially in the case of young people.

‘Particularly concerning is the seeking and granting of orders on an indefinite basis for young adults with learning disability (sic) – something we have reported on in the past<sup>34</sup>’

In legal proceedings, such as an application for guardianship, the burden of proof falls on the person who asserts that capacity is lacking. The court itself must be satisfied that on the balance of probabilities, capacity has been shown to be lacking<sup>35</sup>.

Despite this requirement, in 2015-16 only 1 application for guardianship for a person who has a learning disability was reported by the courts as being ‘declined’<sup>36</sup>. This 1 case was, however, a case where the applicant decided not to proceed.<sup>37</sup> This pattern matches that of the previous year.

It is suggested that the requirement to have the support of medical professionals and a mental health officer for any application for welfare guardianship may act as a deterrent to applications being made for those who do have capacity<sup>38</sup>. This did not reduce the concern of some stakeholder interviewees over the proportion of applications granted.

## 7.2 The high costs and long processing time of guardianships

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In her paper of 2011 proposing the introduction of graded guardianship, the Public Guardian stated:

*'In short, there is concern about every aspect of the current system which, with the increasing volume, is in danger of collapsing.'*<sup>39</sup>

She noted that the cost of applications, at £3,000 on average, presented a significant issue when 9 out of 10 applications were eligible for non-means test Legal Aid. Unfortunately, the Scottish Legal Aid Board does not record data on the sums granted for guardianship orders through Civil Legal Aid, only the number of cases<sup>40</sup>. We can estimate, however, that granting guardianships for people who have a learning disability cost the state around £3m in 2015-16<sup>41</sup> in Legal Aid alone.

In 2011 the Public Guardian quoted the time taken to achieve a guardianship as anything between 3 months and a year. 'Gridlock' in the court process was resulting from the continual increase in the number of applications submitted. In the intervening years, the number of guardianship applications has continued to rise significantly and the system has yet to change.

## 7.3 The financial incentive to request welfare, as well as financial, powers

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An application for support with the legal costs, through Civil Legal Aid, of a welfare guardianship is not 'means-tested'. This means it is available regardless of the financial circumstances of the adult believed to lack capacity, or the proposed guardian. Applications for property or financial guardianships differ; a means test or financial assessment is required. This is, however, based on the resources of the adult believed to lack capacity<sup>42</sup>.

This would seem to incentivise applicants who consider only a property or financial guardianship necessary to also apply for a welfare guardianship, in order to reduce their legal costs. It would certainly seem to be the case when someone who has saved significant sums of money, or owns a property has, for example, lost capacity as a result of dementia.

Whether such an incentive exists in the case of a person with a learning disability is not as clear, since it is their income and capital that is assessed, not the potential

guardian's. Certain welfare benefits mean that Civil Legal Aid is automatically provided, whilst the fact that they are more likely to live in poverty and less likely to be in employment suggests that many will qualify for assistance<sup>43</sup>.

## 7.4 The failure to adopt the least restrictive approach

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Principle 2 of the Adults with Incapacity (Scotland) Act 2000 is that the option chosen must be the one that restricts a person's freedom as little as possible. It was noted by the Public Guardian that guardianship applications commonly request all powers; some of these appeared to be based on a standardised application re-used for a range of clients.

Anecdotal evidence from lawyers appears to confirm this situation. They suggest that such an approach represents a pragmatic solution, that prevents the need for applicants to return to court at a later date to request further powers<sup>44</sup>.

The approach of requesting all powers in an application has also been related to the lack of Legal Aid funding for legal capacity cases (highlighting in bold by the authors):

*'There are increasing current concerns that in many cases serious under-funding of legally aided work under the adult incapacity jurisdiction means that solicitors are not being remunerated for time spent adequately tailoring powers sought to need in each individual case... **The pressures to employ comprehensive "catch-all" lists of powers in all applications are significant.**'<sup>45</sup>*

## 7.5 Courts are not uniformly recognising 'wishes and feelings'

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Principle 3 of the Act requires decisions to take account of 'the present and past wishes and feelings' of the person who is seen to lack capacity. This arose from a determination to avoid the alternative approach of deciding what is in the 'best interests'<sup>46</sup> of the person. This approach is used in other countries, including England.

Despite the clear choice for an approach based on the will and preference of the person who lacks capacity, the Scottish courts continue, in many cases, to base their decisions on the 'best interests' of the person<sup>47</sup>. It is acknowledged that such an approach is not limited to the courts; it is part of a wider issue whereby legal worries based on risk and liability, along with the 'well-intentioned but overly-paternalistic

impulse' to protect vulnerable people, result in professionals choosing the 'best interests' approach<sup>48</sup>.

## 7.6 The lack of support with developing new skills

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Principle 5 of the Act requires that a person should be supported to exercise whatever skills they have concerning property, financial affairs or their 'personal welfare'. They should also be assisted to develop new such skills.

The concern over the number of indefinite guardianships awarded, particularly for young people, and the approach of requesting all powers in applications, both highlighted previously, calls into question whether people are being supported to exercise skills.

The reduction in statutory funding for independent advocacy in Scotland also raises questions as to the availability of impartial support for the development of such skills around decision making<sup>49</sup>.

## 7.7 The failure to give weight to will and preferences

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Despite the five principles of the Act focussing closely on the needs of the person subject to a guardianship, their will and preference is currently not given any prominence over, for example, those of their relatives or carer<sup>50</sup>. There is concern that the closeness of these people to the person subject to guardianship will not always mean that they are able to give an impartial view<sup>51</sup>. The extent to which someone's will and preferences are given weight has not been formally researched<sup>52</sup>. However, our research highlights clearly that the will and preferences of many people who have a learning disability are not being respected, even in relation to the most basic of decisions.

## 7.8 The inability of support for decision making to override incapacity

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Where a person falls under the Act's definition of being 'incapable' due to their inability to communicate alone, they are not judged as lacking capacity if their inability to communicate can be addressed by through the provision of support.

Whilst the provision of decision making support for someone who has a learning disability may also enable them to understand an issue, and therefore exercise their legal capacity, the Act itself does not provide for this situation.

## 7.9 The perception of guardianship as the ‘gold standard’

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The Public Guardian notes that, in particular, financial institutions are the organisations that most rigorously require evidence of an authority to make financial decisions on behalf of someone. This requires the provision of proof of a guardianship order or power of attorney.

Such an approach, whilst important for preventing dishonest behaviour, also creates a situation where a guardianship order may well be sought even when a person who has a learning disability has sufficient ability to make financial decisions.

## 7.10 The challenge in monitoring guardianships

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The Mental Welfare Commission and Office of the Public Guardian are responsible for monitoring welfare guardianships and financial guardianships respectively. Both acknowledge that, whilst they attempt to address the most serious abuses of the system, it is impossible - given the resources available - to address the routine, poor quality rather than unlawful, behaviours of guardians.

Whilst it is right that malevolent behaviour is targeted, this means behaviours that do not represent the spirit of the legislation, and that don't empower those who lack legal capacity, are unlikely to be challenged.

Local authorities also have a role in monitoring welfare guardianships. The Mental Welfare Commission highlights the mounting pressure on local authorities to meet their duty to provide reports on the suitability of guardians<sup>53</sup>. It would seem likely that such pressure is also being felt in relation to monitoring duties, both of guardianships granted to individuals and of situations where a local authority itself has been appointed as guardian.

Where an individual acts as welfare guardian, a local authority supervisor is required to meet with them at least once every 6 months. Despite this, nearly 1 in 3 guardians reported to the Mental Welfare Commission that they were unsure of, or did not

know, who their local authority supervisor was. 1 in 4 said they had not met their supervisor in the past year or more, or had never met a supervisor<sup>54</sup>.

### 7.11 Adults lack an ability to reject, or remove, a guardian

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An adult can, in theory, obtain Legal Aid with which to challenge the appointment of a guardian to substitute their decision-making powers. The very fact that an application has been made, and reports on their alleged incapacity secured, make it highly unlikely that they could, however, instruct a solicitor to represent them.

It is also possible that an adult may believe a guardian to be exceeding their powers. However, if the guardian has a full suite of powers or are able to exert influence, and the adult does not have (or is not allowed to have) any friends/supporters, it is hard to see any way that they could address such a situation.



## 8. PRACTICAL CHALLENGES IN DELIVERING SUPPORTED DECISION MAKING

### 8.1 Understanding the true basis for decisions, rather than a stated preference

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The need to delve deeper than a simple expressed preference, to understand the true basis for a decision, such as fundamental values, is an important part of supported decision making<sup>55</sup>. This could be seen as the difference between supporting the making of a decision, and supporting the exercising of legal capacity.

This represents a challenge when those who should be supporting decision making, such as parents, friends and professionals, are likely to have a limited understanding of what is truly meant by, and entailed in, supporting decision making. The limited availability of independent advocates exacerbates this issue.

### 8.2 ‘Best interpretation’ versus ‘best interests’ in difficult circumstances

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The focus on will and preference in Scotland’s approach to incapacity is in alignment with Article 12 of the UNCRPD and the Committee on the Rights of Persons with Disabilities General Comment No.1. The ability for this approach to work in cases where people have very limited ability to communicate a preference is, however, challenged<sup>56</sup>.

In such circumstances, the expectation of the Committee is that ‘where...it is not practicable to determine the will and preferences of an individual, the “best interpretation of will and preferences”’ should be made<sup>57</sup>.

The Committee’s approach recognises rights, as well as will and preference. It is suggested that, in situations where it is hard or impossible to clarify what a will or preference may be, the person’s rights could instead form the basis of a decision<sup>58</sup>.

### 8.3 The provision of safeguards

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Interviewees noted that the current, legally based, system at least provides some ‘checks and balances’ over undue influence or manipulation. The Committee on the

Rights of Persons with Disabilities also recognises the risk of undue influence, which it defines as being ‘where the quality of the interaction between the support person and the person being supported includes signs of fear, aggression, threat, deception or manipulation.’<sup>59</sup>

There is recognition that a system of supported decision making would require monitoring of ‘the incidence of undue influence, coercion or abuse.’<sup>60</sup> Some argue that safeguards are required to prevent people from putting themselves at risk<sup>61</sup>.

Stakeholder interviewees were of the opinion that Scotland’s adult support and protection legislation and mental health legislation provided safeguards for people who have a learning disability. The criminal law system also provides protection for both people who have a learning disability and those they could perform criminal acts against.

Articles of the UNCRPD were also seen to place a duty on those acting as guardians, and public bodies, to ensure for example, health services are provided without discrimination to people who have a learning disability. This would require someone who is seen to lack capacity to be treated in the same way as someone who doesn’t, meaning they could be required to accept treatment even if they don’t want it if someone with capacity would be treated the same way.

## 8.4 Working with a dispersed team of supports, rather than a single guardian

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Guardians can be seen as being the hub at the centre of a spoked wheel, through whom all decisions the person subject to the guardianship cannot make, must be made. Supported decision making challenges this system; there is no reason why a single person should be at the centre of decision making in such a system. There could be a range of supporters who act in relation to their particular area, or in relation to a particular need.

One stakeholder interviewee highlighted that the support could come from the professional working in the area – the lawyer, doctor or financial adviser – rather than having to come from someone who practices the provision of support or is a family member.

The current system of overseeing guardianship is challenged by the availability of resources. Were such a dispersed arrangement to be created, it is hard to see how this wouldn't amplify the current resourcing issues. It could also present greater challenges in terms of monitoring for undue influence.

## 9. PROGRESS IN THE INTRODUCTION OF SUPPORTED DECISION MAKING

Scotland is not the only country grappling with the UNCRPD Committee's challenge to eradicate substitute decision making. Whilst there has been progress in other countries, none has developed a system that does not have, at some level, substitute decision making. The proposals for reforming the Scottish approach to guardianship also still rely on substitute decision making for some situations. More detail of these proposals, and the progress made in other countries, can be found in Appendix 3.

### 9.1 Terminology used for decision making supporters

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There is no universal term for those who support people with decision making. Terms in use currently include:

- supportive attorney (Victoria, Australia)
- supporter (Alberta, Canada)
- representative (British Columbia, Canada)
- associate decision maker (Yukon Territory, Canada)
- decision-making assistant or co-decision maker (Ireland)
- registered supporter/guardian (proposed for Scotland)
- personal ombudsman (Sweden)

### 9.2 The test for appointing a decision-making supporter

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Several legal jurisdictions have given people with limited decision-making ability a right to appoint someone to support them. A 'catch 22' situation, however, can exist with such an appointment. A person must have some capacity to appoint another to support them. If this requirement is too high, the option will only be available to those who already have sufficient capacity to make their own decisions. Make it too low, and the risk of abuse of the system increases. Different approaches have been adopted to address this issue.

In Alberta, Canada, a supporter may be appointed as long as a person is able to understand the ‘nature and effect’ of authorising someone to support them with decisions. The test in Canada’s British Columbia province is referred to as ‘something less than the capacity to enter into a contract’. A person may make a representation agreement even though they are incapable of making a contract, managing their health care, personal care or legal matters, or the routine management of their financial affairs<sup>62</sup>. However, the level of representation agreement this authorises is limited to ‘routine financial affairs and minor health care issues’; a more comprehensive agreement requires a higher level of capacity<sup>63</sup>.

The test in Canada’s Yukon Territory is relatively simple; an adult may enter into a supported decision making agreement ‘if they understand the nature and effect of the agreement’<sup>64</sup>. Similarly, in Ireland, the person appointing a decision-making assistant must have ‘read and (understood) the information as to the effect of making the appointment’ or, alternatively, the information must have ‘been explained to the appointer, by a person other than the proposed decision-making assistant.’<sup>65</sup>

In contrast, in Victoria, Australia, a person must demonstrate a relatively high level of decision making capacity in order to appoint a supporter. In addition, they must be able to fully comprehend the purpose, limitations, timescales and ability to revoke the arrangement.

Witnesses are used routinely in these jurisdictions to address the risk of someone coercing a person to appoint them as a decision-making supporter. In addition, monitoring arrangements may be required which are included with the supported decision making agreement.

### 9.3 Role of decision making supporters

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A core role description of someone who provides support with decision making can be developed from those systems currently in place across the world. It involves:

- assisting a person to make and express a decision
- assisting them to obtain relevant information, or obtaining it on their behalf
- explaining relevant information
- advising on considerations relating to a decision

- ascertaining the wishes and decisions of the person and assisting them to communicate them
- ensuring that the adult's decision is implemented
- encouraging and facilitating the person to participate, or helping to improve their ability to participate, as fully as possible in decision making

Making decisions on behalf of a person is, unsurprisingly, generally prohibited.

In situations where someone can be authorised to provide support with decision making, their role may still be limited in terms of the decisions that can be supported. A supportive attorney in Victoria, Australia, cannot provide support with significant financial transactions. Similarly, in British Columbia, Canada, a standard representation agreement covers only routine financial affairs and minor health care issues.

In Alberta, Canada, supporters can only be used in respect of personal, non-financial, matters. In contrast, the role of associate decision makers in the Yukon Territory of Canada are not limited; they can address both personal and financial decisions. The same applies to Ireland, where a decision-making assistant can support with decisions relating to personal welfare or property and affairs.

The Swedish Personal Ombudsman service takes a more holistic approach; no legal agreement is required to gain the support of a personal ombudsman and the support is provided according to the priorities of the adult.

## 9.4 Relaxing the definition of capacity

Another way that people can be empowered to make their own decisions is by relaxing the requirement, in terms of capacity, required by someone to make a legally-enforceable decision.

For example, Ireland's Assisted Decision-Making (Capacity) Act 2015 looks at each decision at a point in time<sup>66</sup>. It significantly changes the definition of capacity; rather than being assessed on a 'status' basis, where someone has or doesn't have capacity, it is now assessed on a 'functional' basis<sup>67</sup>. Specifically, the Act states that 'a person's capacity shall be assessed on the basis of his or her ability to understand, at the time that a decision is to be made, the nature and consequences of the decision to be made by him or her in the context of the available choices at that time.'<sup>68</sup>



The following principles, drawn from the international examples, reflects a modern, more functional, approach to the assessment of decision making capacity:

1. There should be a presumption that a person has decision making capacity, until established that they do not
2. Only after all practical steps have been taken to help a person make their own decision should they be treated as lacking decision-making capacity
3. A person may have decision-making capacity for some matters and not others
4. If a person does not have decision-making capacity for a matter, it may be temporary and not permanent
5. The fact that a person is able to retain the information relevant to a decision for a short period only does not prevent them from having decision-making capacity
6. Decision-making capacity should not be determined on the basis of the person's appearance or the way they communicate, for example, through sign language or assistive technology
7. A person who makes a decision that is, in the opinion of others, unwise does not necessarily lack decision-making capacity
8. A person is able to understand information relevant to a decision if they are able to understand an explanation of it given to them in a way that is appropriate to their abilities or circumstances
9. A person has decision-making capacity for a matter if it is possible for them to make a decision in the matter with practical guidance and appropriate support

## 10. CONCLUSIONS

### 10.1 From the peer research

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The core question we sought to answer through the peer research was ‘does it matter to people with learning disabilities whether they are supported in their autonomous decision-making or have substitute decision-makers in their lives?’ In addition, we wanted to understand what people experienced as good support for decision making, and how this could develop our understanding of how a progressive supported decision-making system would operate.

The evidence from the peer research clearly indicates that most participants prefer to make their own decisions in most situations, both at an ‘everyday’ level and in more complex and perhaps challenging circumstances. These include living independently, making friends and finding a partner, and managing budgets and support staff. Having the freedom to act, and to be supported to act, as independently as possible is strongly correlated to the idea of individual and personal development and growth, and the transition to adulthood.

When people make their own choices and decisions it makes them happy, and they feel valued and in control of their lives, and enabled to play a fuller part in wider society through, for example, work and volunteering. This is especially the case where they are strongly connected with people that know them well, and that they know and trust, who can help them to make decisions as needed. This includes family members, friends, support staff, and specialists e.g. lawyers and advocates.

Participants attribute the successful development of these relationships to ‘being genuinely listened to’; to people making and taking the time to really get to know them and for mutual trust to be developed. The importance of being encouraged to take risks, make mistakes and learn from experience cannot be overstated. It breeds confidence, deepens relationships and encourages further risk taking.

These trusting relationships are all the more necessary when people find decision making difficult and stressful. A safe space and supported time to think are essential when, for example, low mood/confidence or worry about going against loved one’s wishes are part of the equation. The opportunity to seek the views, ideas, opinions and advice of trusted people in coming to a decision is highly appreciated.

Conversely, decisions taken for or about people ‘behind their backs’, without genuinely consulting them or by ignoring their views are experienced as excluding, devaluing and disempowering people and ultimately discriminatory. This is particularly the case where people are routinely told they are not able and/or not allowed to make some decisions.

These decisions appear to fall mainly into 2 categories:

- decisions that may be perceived to carry a higher risk e.g. around the potential for sexual relationships, where to live; and
- decisions around boundaries that restrict individual freedom(s) e.g. when to go to bed, where you can go out independently, when to be back by - often associated with living in communal / residential establishments.

The vignettes (section 5) and case studies (appendix 2) clearly demonstrate the value of good supported decision making. They evidence openness, expression and discussion of fears and apprehension by both the person being supported and the supporter. They demonstrate how support is provided in a way and at a pace that is inclusive and empowering and how that helps the person to make informed decisions, and take meaningful risks, from which everybody learns and benefits.

## 10.2 General conclusions

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This research project set out to answer the question ‘can supported decision-making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision-making?’ To help answer this, we sought to answer three specific questions.

### **1. Does it matter to people with learning disabilities whether they are supported in their autonomous decision-making or have substitute decision-makers in their lives?**

We found through the peer research, as outlined above, that it really does matter to people who have a learning disability that they can make autonomous decisions. We also found beacons of good practice already in existence in Scotland.

## **2. Would substitute decision-making still be needed for some people or for some kinds of decisions?**

The answer to the question as to whether substitute decision-making is still needed for some people, or for some kinds of decisions, is more challenging. The Committee on the Rights of Persons with Disabilities clearly believes it is possible, but they are not required to develop legislative proposals that are subject to scrutiny by a parliament.

The review of developments in supported decision making across the world has not highlighted any state that has successfully, wholly, eradicated substitute decision making. However, there are some notably progressive solutions whereby supported decision making has replaced some elements of substitute decision making. This raises the question as to why further progress on supported decision making hasn't been made outside of these few, progressive, jurisdictions.

The answer to this may lie partially in the answer to the question as to how might 'decision-making supporters' be defined, authorised and monitored. It is clear that resources and risk play a significant role in these decisions, and therefore act as fundamental blocks to progress.

This question clearly requires further study and research and, ideally, pilot projects which can explore the mechanisms and processes to establish whether it could work, especially in relation to the "hard cases" where people's ability to express will and preference is impaired.

## **3. How might the 'decision-making supporters' be defined, authorised and monitored?**

In Scotland, there is agreement between the Mental Welfare Commission and Office of the Public Guardian that a form of graded guardianship should be introduced. There is, however, no clear agreement as to who should bear the burden of authorising and monitoring those defined as decision-making supporters.

Scottish local authorities are clearly struggling to fulfil their current duties, without taking on an additional role. The Mental Welfare Commission reports that it is reviewing the number of guardianship visits it undertakes 'to ensure the financial sustainability of the Commission.'<sup>69</sup> The Public Guardian has previously been explicit about the pressures her organisation faces.<sup>70</sup>

Risk, and the perceived need to safeguard people who have a learning disability (and possibly the public from them) is not just restraining progress in Scotland. Even some of the most positive examples of legislative change, like Alberta in Canada, have been restricted (in this case, to non-financial decisions) apparently due to risk of abuse.

The approach taken in Sweden appears to be worthy of more investigation. The injection of resources at national and local level, and a very free approach to the autonomy of the person who has a learning disability, appears to have delivered measurable success against a number of indicators.

The key to the Swedish personal ombudsman system's success appears to be their skill in working with those they support to make decisions. Within Scotland, fundamentally poor practice appears to exist in the way those involved with decision making perform their task. It does not appear to matter whether this is under a formal relationship, such as a guardianship, or whether someone is acting in a self-appointed decision-making role.

Research participants highlighted how some guardians failed to recognise their right to make their own choices. This is unsurprising; wider society still has significant progress to make in viewing people who have a learning disability as equal citizens.

It would be incorrect to characterise all of those who fail to provide good support for decision making as malevolent. Those appointed as guardians may simply lack the necessary skills to make what may be significant life decisions on behalf of someone else. There is, after all, no requirement on a guardian to undertake training or meet any specified standard.

Can supported decision-making for people with learning disabilities offer a practical, safe and realistic alternative to substitute decision-making? The evidence suggests it can in most, if not all, cases – but only with a significant change in mindset as to rights, resources and risks involved.

Fundamentally, making one's own decisions about one's own life is no less important to people who have a learning disability than it is to any other citizen of Scotland.

## APPENDIX 1 – FOCUS GROUPS ACROSS SCOTLAND

	Area	No of Participants
1	Pilot Group	5
2	Midlothian 1	3
3	South Lanarkshire	5
4	Perth	3
5	Fife 1	8
6	Fife 2	6
7	Fife 3	11
8	Fife 4	8
9	Dundee	6
10	East Lothian	9
11	Aberdeenshire	11
12	Edinburgh 1	7
13	Edinburgh 2	9
14	Edinburgh 3	8
15	Edinburgh 4	6
16	Midlothian 2	2
17	Midlothian 3	6
18	Glasgow 1	6



(Cont)	Area	No of Participants
19	Glasgow 2	5
20	West Lothian 1	8
21	West Lothian 2	5
	Group total*	137
	<b>Actual total</b>	<b>128</b>

\* The Group Total varies from the Actual Total due to the fact that 9 participants took part in more than one focus group. For example, the 5 members of the Pilot Group also participated in their local area focus group.

## APPENDIX 2 – CASE STUDIES

### Case study 1

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#### Case Study 1:

**Tell us about a time when someone helped you to make a decision that was important to you, where you found their support very helpful.**

I've had to make decisions quite a few times. I need easy read information and an advocacy worker who knows about me.

I made the decision to give up my work and take on the responsibility of looking after my son fulltime. My son has quite complex needs. I am now my son's carer.

#### **What was happening?**

My son's mum had his care and she was not coping very well. She couldn't manage. I had put my name forward and had to persuade them (social work) that I was relevant, that I could be a good dad for my son.

#### **What were you doing?**

I was wanting to look after my son. I was also working and I liked that. I didn't know anything about looking after children. My advocacy worker made sure I got the right advice.

Other professionals were very sceptical of me being able to manage caring for my son because of my learning disability.

If you need to get help from someone to make a decision, they've got to know you. You need to have a relationship prior to going into this process. You need to have confidence on the person that is with you, helping you.

#### **Who helped you make those choices?**

There a few people involved, worked together:

My advocacy worker.

My local area co-ordinator.

An independent social worker – was really good, great, totally independent, knew about learning disability. Helped me get evidence to prove I was able to be my son's carer. She played a key part. It would not have worked if she was not independent. We fought for it and it was worth it. It made a big difference.

Child and adolescent mental health worker – understood my son very well. She had a big influence in my decision. She taught me sign language and how to understand his behaviour.

### **Why did you want them to help you out?**

A lot of it was about self-belief and motivation.

I also needed help because I didn't understand the implications fully, especially the financial ones. I needed to know about the respite arrangements as well.

Mentally, it was taking a lot out of me. One decision would have knock on effect on my whole life.

### **What was important to you about the person who helped?**

That they know what a learning disability is and I don't just mean reading it from a book. It doesn't mean you have the experience.

Independent, reliable, trustworthy, that you know them from before.

They need to take genuine interest in helping you, more than just a job.

### **How did they support you to make those decisions?**

We discussed the options, if I go down this route or the other, what would it be like. Nobody else was explaining that to me.

They gave me the time I needed and worked with me, my strengths and my weaknesses.

They made accessible resources of the diagrams and information.

### **What were the most important and helpful things they did to help you make up your mind and decide what to do?**

My advocacy worker was a good person to bounce off different ideas from. Getting the time to work things through and understand it. She 'translated' the legal jargon for me.

**Is there anything else you wish they had done to help you?**

I would have liked them to be there a wee bit longer. I learned so much from them (and they also learnt from me).

**Were you pleased with the decisions you made with their help?**

Yes, I was pleased. The outcomes are much better.

The more input we have ourselves, the better we feel about ourselves. Getting support with decisions helps you stay involved.

**How did it make you feel to have support to make this decision?**

You've got to have a strong belief in yourself. You've got to know what you can or cannot achieve. You have to know your weaknesses and get help for them.

I never thought I would have got to make this decision to begin with. The help was key and improved my understanding. It was important to me to go through the finer details. To understand all the words, it helped me learn the meanings.

## Case Study 2:

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**Can you think of a time when someone helped you to make decisions (choices) that were important to you, where you found their support helpful?**

My support from People First when someone sat with me at the computer to choose which properties to put a bid in. There was some confusion about which properties to go for. They would sit down beside me at the computer. It would have been hard to figure out which flats I was eligible for. They helped explain, look at different areas, where the houses were that I could bid for. They explained how Edindex works. We looked at all the information on the website about each flat. I knew how to get into Edindex but not how the new system works. I would have been stuck.

My support staff took me down to show me where it was. When I saw the building and the area, I thought 'I couldn't be more perfect'. It is also close to the People First office and dominoes.

I think, without all the support and help, I would still be homeless and staying in that dreary B&B which is not a place for a person with a learning disability.

My Housing Officer at the Action group invited me to a meeting to talk about my options. The options they offered me were about the help I could get to move into my new property. They are offering me a lot of support with practical things, like moving furniture, getting the flat painted, getting the letterbox fixed. I had to choose the colour of the carpet that I wanted. I could ask all the questions I wanted. Knowing that vital support was there was incredible.

### **Can you tell us more about that time?**

I was made homeless and I ended up getting support to go to the Council to explain my circumstances, to find somewhere to stay. I went to Salvation Army but it was not the right place for me so I had to go back to the Council. They put me in a B&B which was handy but had its issues.

My support staff understand what I'm going through. They agreed with me that the B&B was not the place for a person with a learning disability. They helped me get a flat as soon as possible.

My housing officer helped me choose a place to live. They said 'we have a property', where it is, what it looks like. My support staff came with me to see it. I had a series of meetings on a weekly basis with my housing officer. At the second meeting, I got to see the inside of the flat and they asked me how I feel about it.

I was thinking 'Would I take it? Would it make me feel safe?'

They also asked me questions in relation to what I needed. Would I want blinds or curtains? What colour would I paint the walls?

They asked me what colour carpet I would want, showed me examples (samples) and I chose the one I wanted. I was supported to go through the options one by one. Would I like this or that colour? That carpet or this one? They had examples for all of them.

They also explained to me what the options were for blinds or curtains. I chose a type of blind because it would be easier for me to use. I said 'I'll go for those blinds, please'.

I went away and made a list of stuff I needed. I was happy with my decisions. I more or less had my mind made up. I know how I want to decorate.

My support staff have been to meetings with me, supporting me, helping me ask the right questions, helping me understand everything that's being said. I think it's important for me to have support in those meetings.

They are doing everything that they can at the moment. If I was left to do it by myself, I'd be really struggling.

**Were you pleased with the decisions you made with their help?**

Yes, definitely. Because if I didn't get a choice and feel fully involved in the decisions, I would have found that really frustrating.

### Case Study 3:

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**Think of a time when someone helped you to make decisions (choices) that were important to you, where you found their support very helpful?**

I recently moved house and needed support to make some decisions around this.

**Can you tell us more about that time – the story of that time.**

**What was happening** – I was struggling with the stairs in my flat due to my health. The toilet and the bedroom were upstairs. I needed somewhere more suitable to live.

**What were you doing?** - Continuing to struggle and my health was getting worse. I had gone on the Council list but was struggling to get anywhere on the ground level. I was on oxygen and was finding it difficult to get in and out the flat. I had support from my advocacy worker to look for a private house on the ground floor. We spent time looking on the laptop and identifying houses that were suitable. We then went to view them together. I had just decided to buy one when the Council came up with a suitable downstairs flat. I then looked at the options and decided to take the Council house. This needed a lot of discussion and support as it was a big decision, especially financially.

**Who helped you make those decisions?** – Advocacy worker, support staff, flatmate, my trustee and friend.



**Why did you want them to help you?** - Because I wouldn't have known where to start. I trusted them to have my best interests at heart. I knew that they would help me think about the best option for my flatmate too.

**What was important to you about the person or people who helped?** It was important for them to know what my needs were and that they understood that it wasn't just about me but my flatmate needed to be taken into consideration too. It was important that the person was able to listen to me and let me make my own decisions with the help that they gave me. I didn't want anybody telling me what to do or being bossy.

**How did they support you to make those decisions?** They helped me look at the options and weigh up what the best thing for both of us was. They talked things over with me. They helped me look at what my needs were. I needed to know what the financial implications were and these were spoken about and explained so that I was able to come to a decision.

**What were the most important and helpful things they did to help you make up your mind and decide what to do?**

Practical things like filling in forms and doing phone calls, help to view houses, help with furniture and moving in, help with removals, help with suppliers, and help to look at my local area. Emotional support was also offered and was very important. They helped me talk to my flatmate and explain things and also to help me manage his anxiety (and my own anxiety). They helped me understand information in an easy read format.

**Is there anything else you wish they had done to help you?** - I was able to ask for all the support I needed because I was close to the people who helped me and I trusted and knew them well. They also knew me well and cared about my welfare. There was no other support that I needed.

**Were you pleased with the decisions you made with their help?** - Very pleased, it was an easier and less stressful process because I had the right support. It was also easy for me to ask for what I needed because the people who helped me were friendly, supportive and approachable. I now live somewhere I can access easily and this has had a positive impact on my life.

## APPENDIX 3 – PROGRESS IN OTHER COUNTRIES

### 1. Australia – pilot projects and proposals

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There are similarities in the drivers for change in Australia and the UK, including a rapid rise in guardianship orders and the ignorance of the principles under which guardians should operate<sup>71</sup>.

Six, small scale, pilots were conducted for 1-2 years that aimed to promote the use of support for decision-making. Killeen (2017) reports that:

‘The supported decision-making models in Australia demonstrate positive outcomes for people with cognitive disabilities and their supporters as well as exposing issues to be addressed by more rigorous research than has been accomplished so far. A new series of pilot projects are underway with collaboration between several research institutes and it will be important to follow their progress. However, a whole population response is necessary if negative social attitudes and systemic barriers are to be challenged to recognize people with cognitive disabilities as full citizens with all the same legal rights as everyone else.’

In 2014, the Australian Law Reform Commission proposed a reform of incapacity legislation based on four principles<sup>72</sup>:

- **Principle 1: The equal right to make decisions** - All adults have an equal right to make decisions that affect their lives and to have those decisions respected.
- **Principle 2: Support** - Persons who require support in decision-making must be provided with access to the support necessary for them to make, communicate and participate in decisions that affect their lives.
- **Principle 3: Will, preferences and rights** - The will, preferences and rights of persons who may require decision-making support must direct decisions that affect their lives.
- **Principle 4: Safeguards** - Laws and legal frameworks must contain appropriate and effective safeguards in relation to interventions for persons who may

require decision-making support, including to prevent abuse and undue influence

The model ‘provides for and strongly preferences supporters (appointees without substitute decision-making powers) but also includes provision for “representatives” (last resort appointees carrying proxy decision-making powers)’<sup>73</sup>. The Committee on the Rights of Persons with Disabilities has expressed concern at the retention of substitute decision making<sup>74</sup>.

## Victoria

Under the Powers of Attorney Act 2014, an adult (aged 18 or over) may appoint one or more supportive attorneys. The adult can authorise a supportive attorney to ‘access, collect or obtain information; to communicate, or assist the principal to communicate supported decisions; or to do anything that is reasonably necessary to give effect to supported decisions (other than decisions about significant financial transactions).’<sup>75</sup>

An adult is judged to have sufficient decision making capacity to appoint a supportive attorney if they are able to:

- (a) understand the information relevant to the decision and the effect of the decision; and
- (b) retain that information to the extent necessary to make the decision; and
- (c) use or weigh that information as part of the process of making the decision; and
- (d) communicate the decision and the person's views and needs as to the decision in some way, including by speech, gestures or other means<sup>76</sup>.

In relation to (a) above, the adult ‘is taken to understand information relevant to a decision if the person understands an explanation of the information given to the person in a way that is appropriate to the person's circumstances, whether by using modified language, visual aids or any other means.’<sup>77</sup> Specifically, they must understand:

- (a) that the appointment enables the principal to make and give effect to his or her own decisions with support; and

- (b) that the appointment allows the principal to choose a person to support the principal to make and give effect to his or her own decisions; and
- (c) that supported decisions are decisions of the principal and not the supportive attorney; and
- (d) when the appointment commences; and
- (e) that the principal may revoke the appointment at any time when the principal has decision making capacity in relation to making the supportive attorney appointment.<sup>78</sup>

A determination of capacity should take into account that:

- (a) a person may have decision making capacity for some matters and not others;
- (b) if a person does not have decision making capacity for a matter, it may be temporary and not permanent;
- (c) it should not be assumed that a person does not have decision making capacity for a matter on the basis of the person's appearance;
- (d) it should not be assumed that a person does not have decision making capacity for a matter merely because the person makes a decision that is, in the opinion of others, unwise;
- (e) a person has decision making capacity for a matter if it is possible for the person to make a decision in the matter with practicable and appropriate support.<sup>79</sup>

## 2. Bulgaria – a draft bill

In their 2016 report to the UN Human Rights Committee, Bulgaria highlighted that a draft Natural Persons and Support Measures Act (NPSMA) has been produced which, according to their report:

‘...contains all principles and standards, provided in Art. 12 of the Convention on the Rights of Persons with Disabilities, and a fundamental value change is introduced in the regulation of capacity, with full coverage of the recommendations for legislative reform as given in General Comment No. 1 (2014) by the United Nations Committee on the Rights of Persons with Disabilities. The draft Act provides for the state to develop support

mechanisms for everyone to enjoy their rights independently and make their personal choices, including those with disabilities, on equal basis with others, in accordance with their will, values, and preferences.’<sup>80</sup>

The Act’s measures include ‘referring the person to a community-based social service to help improve their skills and identifying an individual who has a relationship of trust with the adult and who can consent on their behalf in relation to certain legal actions.’<sup>81</sup>

### 3. Canada – a variety of approaches in law

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#### Alberta

Alberta’s Adult Guardianship and Trusteeship Act 2008 provides a mechanism by which an adult can appoint someone (a supporter) to assist them to make decisions. To do so, the adult must be able to understand ‘the nature and effect of a supported decision-making authorization.’<sup>82</sup> The adult can authorise their supporter:

- (a) to access, collect or obtain or assist the adult in accessing, collecting or obtaining from any person any information that is relevant to the decision and to assist the adult in understanding the information;
- (b) to assist the adult in making the decision;
- (c) to communicate or assist the adult in communicating the decision to other persons.<sup>83</sup>

Supported decision making authorisations can only apply to personal, nonfinancial, matters.<sup>84</sup>

#### British Columbia – Representation Agreements

The Representation Agreement Act 1996 enables an adult to enter into a representation agreement with another who will support them with decision making<sup>85</sup>.

An adult making such an agreement does not need full legal capacity to make a standard agreement, which can be used for ‘routine financial affairs and minor healthcare issues’. The test is ‘something less than the capacity to enter into a contract’, the Representation Agreement Act specifying that:

...all relevant factors must be considered, for example:

- (a) whether the adult communicates a desire to have a representative make, help make, or stop making decisions;
- (b) whether the adult demonstrates choices and preferences and can express feelings of approval or disapproval of others;
- (c) whether the adult is aware that making the representation agreement or changing or revoking any of the provisions means that the representative may make, or stop making, decisions or choices that affect the adult;
- (d) whether the adult has a relationship with the representative that is characterized by trust.<sup>86</sup>

An enhanced or comprehensive Representation Agreement can cover all matters, including end of life decision making<sup>87</sup> but ‘these agreements do not allow for a role of supporters; the section refers to the representative being authorized to do certain things, but there is no mention of a role for helping in decision-making.’<sup>88</sup> They also require a higher standard of legal capacity of the adult appointing the representative.

The Representation Agreement Act has been described as ‘innovative legislation that achieves a delicate balance for enabling self-determination and providing safeguards’<sup>89</sup>. One of the purposes set out in the Act is to ‘Avoid the need for the court to appoint substitute decision-makers when they are incapable of making decisions independently’<sup>90</sup>

## Yukon Territory

The Decision Making, Support and Protection to Adults Act 2003 of the Yukon facilitates supported decision making covering both financial and personal decisions. The responsibilities of the supporter appointed by an adult, referred to as an ‘associate decision maker’, are:

- (a) to assist the adult to make and express a decision;
- (b) to assist the adult to obtain relevant information;
- (c) to advise the adult by explaining relevant information and considerations;
- (d) to ascertain the wishes and decisions of the adult and assist the adult to communicate them; and
- (e) to endeavour to ensure that the adult’s decision is implemented<sup>91</sup>.



There is flexibility regards the contents of the decision-making agreement, but it cannot give the associate authority to substitute the adult's decisions.<sup>92</sup>

#### 4. Ireland – assisted and co-decision making implemented

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Ireland's Assisted Decision-Making (Capacity) Act 2015 introduced Assisted Decision Making and Co-Decision Making<sup>93</sup>. These arrangements are available to a person over 18 who considers that their 'capacity is in question or may shortly be in question'<sup>94</sup> and can cover 'personal welfare or property and affairs'.

A formal agreement is used as the basis for a Decision-Making Assistant, which can be revoked by either the adult or Decision-Making Assistant. The Decision-Making Assistant can:

- (a) assist the appointer to obtain the appointer's relevant information,
- (b) advise the appointer by explaining relevant information and considerations relating to a relevant decision,
- (c) ascertain the will and preferences of the appointer on a matter the subject or to be the subject of a relevant decision and assist the appointer to communicate them,
- (d) assist the appointer to make and express a relevant decision, and
- (e) endeavour to ensure that the appointer's relevant decisions are implemented.<sup>95</sup>

They are not permitted to make decisions on behalf of the adult i.e. to perform substitute decision making.

More than one Co-Decision Maker can be appointed by an adult but they must be 'a relative or friend of the appointer who has had such personal contact with the appointer over such period of time that a relationship of trust exists between them.'<sup>96</sup> They can:

- (a) advise the appointer by explaining relevant information and considerations relating to a relevant decision,
- (b) ascertain the will and preferences of the appointer on a matter the subject of, or to be the subject of, a relevant decision and assist the appointer with communicating the appointer's will and preferences,

- (c) assist the appointer to obtain the appointer's relevant information,
- (d) discuss with the appointer the known alternatives and likely outcomes of a relevant decision,
- (e) make a relevant decision jointly with the appointer, and
- (f) make reasonable efforts to ensure that a relevant decision is implemented as far as practicable.<sup>97</sup>

Decisions are made jointly between the Co-Decision Maker and the adult. The Co-Decision Maker must accept the wishes of the adult in respect of a decision covered by their agreement, unless this would result in serious harm to the adult or to another person<sup>98</sup>.

A functional measure of capacity is used within the Act. An adult only lacks capacity if they are unable to:

- (a) to understand the information relevant to the decision,
- (b) to retain that information long enough to make a voluntary choice,
- (c) to use or weigh that information as part of the process of making the decision, or
- (d) to communicate his or her decision...or, if the implementation of the decision requires the act of a third party, to communicate by any means with that third party.<sup>99</sup>

A person does not lack capacity if they:

- Require information to be explained to them in a way that is appropriate to their circumstances
- Can only retain the relevant information for a short period of time
- Did lack capacity for a particular decision at one time but may no longer lack capacity to make that decision
- Lack capacity for some decisions but have capacity to make decisions on other matters<sup>100</sup>

The Act also makes provision for substitute decision making, through the court appointment of a Decision-Making Representative.

## 5. Northern Ireland – new legislation, still substitution

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The Mental Capacity Act (Northern Ireland) 2016 contains 5 key principles<sup>101</sup>:

- There is a presumption that a person has mental capacity unless proved otherwise
- Only after all practical steps have been taken to help a person make their own decision, should they be treated as incapable of doing so
- It should not be presumed that a person lacks mental capacity just because they make an 'unwise' decision
- Any acts carried out on someone's behalf should be done in their best interests
- Before acting for a person lacking mental capacity, consideration should be given as to the least restrictive way of achieving the desired outcome

A person's capacity to make a decision is based on a two-stage decision:

**Stage 1** – does the person have an impairment of, or a disturbance in the functioning of, the mind or brain.

**Stage 2** - Can the person:

- Understand information relevant to the decision?
- Retain that information long enough to make the decision?
- Use or weigh up that information when making the decision?
- Communicate their decision whether by talking, using sign language or any other means?

If there is reasonable belief that the person meets the test in stage 1, and any of the four criteria in stage 2, then the person does not have capacity for the decision in question<sup>102</sup>.

## 6. Scotland - graded guardianship proposals

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Some form of graded guardianship was the most popular suggestion for revisions to the Adults with Incapacity Act during a recent Scottish Government consultation<sup>103</sup>. The proposal from the Office of the Public Guardian and Mental Welfare Commission

features three levels, with the Public Guardian wishing to see supported decision making underpinning all levels<sup>104</sup>:

- **Grade 1: ‘registered supporter/guardian’ model, for possibly 20% of cases** - envisaged as a practical and realistic model for straightforward cases, which aligns with the UNCRPD concept of supported decision making. Formal status could be achieved by the supporter, who could be a family member or friend, without the need for full guardianship. Evidence would be needed that the appointment was the will and preference of the adult to be supported. Registration could be with a local authority, the Mental Welfare Commission or Office of the Public Guardian.
- **Grade 2: for more complex, but non-contentious cases** - designed for both individuals and local authorities, it is not envisaged as being used against the will of an adult or where there is a dispute amongst interested parties. The application process would require a medical certificate of incapacity and support from a category of professional wider than the current mental health officer. An application would be made to a local authority or the Office of the Public Guardian.
- **Grade 3: substitute decision making model** - operating similarly to the current guardianship arrangements, permitting decision making at odds with the will and preference of the adult. Applicants would be required to involve the adult concerned and establish their will and preference, the medical reports required could reduce from two to one and there would be an automatic periodic review.

The proposal appears to retain the concept of guardianship and substitute decision-making in grades 2 and 3, albeit with a proposed increase in the use of support in determining the person’s wishes.

## 7. Sweden – a non-legal approach

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An entirely different approach to supporting decision making was adopted by nation-wide in Sweden in 2000. Those responsible for its development talk of a desire to ‘combat the argument of guardianship “as a last resort” for (persons with the most severe psychosocial and intellectual disabilities) - by showing through concrete examples, that guardianship and other forms of ‘substituted decision-making’ aren’t necessary.’<sup>105</sup>

A 'personal ombudsman' works solely for the benefit of an individual. No legal agreement or bureaucratic procedures are required to get a personal ombudsman. The adult may find the ombudsman directly, a statutory service may introduce them, or a user-organisation may provide the link.

Support is provided according to the priorities of the adult; these may not be the same as those of the authorities or relatives. The relationship may be in place for many years.

Personal ombudsman services are provided by a range of organisations, including local authorities and non-governmental organisations (NGOs). The cost is financed 2/3 by the state and 1/3 by the local authority<sup>106</sup>.

## APPENDIX 4 – CONSENT AND EVALUATION FORMS

### Consent form for DRILL Research



I am an adult over the age of 18.

I have a learning disability. I believe that I have the right to decide, for myself, whether to take part in this research or not. I may need to keep my experience private and if so will not share it.



I have volunteered to take part in the DRILL research about decision-making.

I understand what decision-making means.



I understand that I can leave at any time and not answer any questions I do not want to answer.

I understand that I can ask for support from anyone if I need help to understand something.



I do not feel that anyone has pressured me into taking part.

I give my consent for the researchers to ask me questions about decision-making and about my experiences and thoughts and ideas on decision-making and to use those things in the report.



I know that anything I say will be anonymous. This means the report will not say what my name is. What I said in the Focus Group is private to the group. The groups agree but cannot be made to keep what is said private.

Signed \_\_\_\_\_

Date \_\_\_\_\_

The Code of Practice of the Adults with Incapacity Act clarifies that; an adult does not have impaired capacity simply by virtue of having an addiction, psychotic illness or learning difficulties and disabilities.





## DRILL monitoring questions

Our research is about making decisions.

Making decisions is part of independent living.

How much do you know and understand about independent living for people with Learning Disabilities?



A lot	A bit	Not much	Nothing at all	Don't know

How much do you know and understand about how people with learning disabilities make decisions?



A lot	A bit	Not much	Nothing at all	Don't know

How much do you know and understand about organisations and services that support independent living for people with learning disabilities?



A lot	A bit	Not much	Nothing at all	Don't know

Has taking part in the focus group made you think more about decision-making and independent living?



Yes, a lot	Yes, a bit more	The same	No, not at all	Don't know

After taking part in the focus group do you know and understand more about decision-making and independent living?



Yes, a lot more	Yes, a bit more	The same	No, not at all	Don't know

How confident do you feel about being able to live independently?



Very confident	Quite confident	Not very confident	Not confident at all	Don't know



Has taking part in the research made you more confident about decision-making and independent living?



Yes, a lot more	Yes, a bit more	The same	No, not at all	Don't know
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How involved do you feel in the planning and delivery of the services you get? For example, your housing and support services



Very involved	Quite involved	Not very involved	Not at all involved	Don't know
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Do you think taking part in the research will make you want to get more involved in the planning and delivery of the services you get?



Yes, a lot more	Yes, a bit more	Not much more	Not at all	Don't know
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Has taking part in the research helped you think more about how you want to make decisions in your life?



Yes, A lot more	Yes, a bit more	Not much more	Not at all	Don't know
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# **Animate Consulting**

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