What is “fair and reasonable”? Norms and strategies guiding the distribution of assets by testators who have an adult child with intellectual disability

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ABSTRACT

Background: Parents making a will most commonly distribute assets evenly to adult children. How parents of an adult child with an intellectual disability use wills to plan for future care and support has had limited policy, practice and research attention.

Method: This research reports on the perceptions of 20 parents regarding the impact of the needs of their child with disability on estate planning. The participants were purposively recruited and interviewed during 2014–15.

Results: Participants were more likely to consider equity of outcomes for their children taking into account retaining access to state services. They report difficulties in future planning in the context of changing service systems and limited specialised advice.

Conclusions: Judgements about what is fair and reasonable in distributing assets reflect differing views of need and entitlement within families. Such families would benefit from specialised advice and support in estate planning, particularly given the changing context.

KEYWORDS

Intellectual disability; families; wills; inheritance

Points of interest

• Most parents making bequests to their children prioritise equality over need and equity.
• In making bequests, parents of an adult child with an intellectual disability are more likely to consider equity and need, although some follow the principle of equal shares.
• Such parents experience difficulty in future planning in the context of changing service systems, limited specialised advice and a concern to protect existing income support, housing and services.

An assessment by parents of what is a fair and reasonable distribution of assets to children in their wills is influenced by a number of factors including legal frameworks, cultural beliefs, past promises and contributions, the nature and quality of relationships and the assessed relative needs of potential beneficiaries (Tilse, Wilson, White, Rosenman, & Feeney, 2015a). These can be complex decisions and this is particularly so for parents of adult children with an intellectual disability.

Internationally there are significant legal and cultural differences across countries in the views on inheritance and the consequent principles guiding intergenerational transmission of wealth (Goodnow & Lawrence, 2010). Australian (and also in New Zealand, Canada and the UK) succession law is based upon English common law starting with the presumption of testamentary freedom, which allows a testator to dispose of their estate as they see fit. This freedom is limited by family provision laws that allow “eligible applicants” to contest distributions on the basis of insufficient provision in accordance with legislation of the particular State or Territory (Croucher, 2012; Rowlingson, 2002). Hence, the legal framework represents a balance between testamentary freedom and familial obligation. In Australia, State Public Trustees who are acting for adults with intellectual disability will review asset distributions by estates to decide if the distribution should be challenged.

Research indicates that traditional inheritance norms and obligations can be impacted by broad cultural and policy changes (Wilson, Rosenman, White, Tilse, & Feeney, 2014) and hence affect perceptions of what is a “fair share” in the context of a child living with an intellectual disability. It is clear that community views vary on what constitutes an acceptable quality of life for people in this group and who should pay for this.

Since 2013, significant changes have occurred in Australia in the structure and funding of services for people with disability with the staged introduction of the National Disability Insurance Scheme (NDIS). The
scheme shifts the focus from funding services, which generally determined what needs would be met, to funding eligible individuals who were to have choice and control of what services were needed. Payments reflect the cost of meeting what are assessed as “reasonable and necessary” needs caused by the disability, are not means-tested and will not impact on government income support programs such as the Disability Support Pension (DSP) (Transitioning to the NDIS, August, 2019). People with intellectual disability may well need considerable support from their nominees (usually family members) to identify and express needs and decide how they are to be met. This change in the funding model squarely places responsibility for organising such support with individuals and families rather than services.

Along with defining future goals for their child with a disability, parents when making or changing a will are concerned with distributing assets fairly to family members, and maintaining good relationships between their adult children, who they hope will provide support to their sibling with intellectual disability.

**General distributive principles: Norms within families**

Testators generally give primacy to intimate and biological family relationships, and their support needs, particularly concerning children (Douglas, Woodward, Humphrey, Mills, & Morrell, 2011; Gilding, 2005). It is argued that no single norm or motive guides decisions about inheritance (Goodnow & Lawrence, 2010) and that material, moral and symbolic dimensions can create competing norms (Finch & Mason, 2000). Balances are also struck between leaving and spending an estate, the relative importance of individual and family rights, recognition of relationships and of past contributions. Having a child with intellectual disability and an ongoing need for care increases the complexity.

A four-year project examining the prevalence and dynamics of making, changing and contesting wills in Australia reports 59% of Australians had a will and most of the remainder intended to make one. The overwhelming majority (n = 1090, 93%) of respondents with children stated that they would provide equal shares to their children. Respondents’ reason(s) for leaving unequal shares for their children included their status as biological or step children, a perception that one child had greater financial need or was more or less deserving, in terms of their behaviour or misfortune (Tilse et al., 2015a). Overall, participants saw wills as family documents, that most assets should be kept in the family and that generally wills should provide equal shares for all children (Tilse, Wilson, White, Rosenman, & Feeney, 2015b). An earlier Australian study found that “equality”, i.e., equal shares, was the overriding principle for asset distribution (Drake & Lawrence, 2000). It is suggested that unequal shares may result in “dissatisfaction, conflict, and the breakdown of relationships among expected beneficiaries” (Drake & Lawrence, 2000, p. 272). These findings echo a UK study of public attitudes to inheritance law, which determined that participants generally considered it fair to treat all children equally in wills regardless of the child’s personal circumstances (Douglas et al., 2011).

**Asset distribution when a child has an intellectual disability**

Despite a general norm of equality, situations exist where the unequal distribution of testator assets is considered acceptable, particularly where a child’s needs require significant resources (Goodnow & Lawrence, 2010; Sousa, Silva, Santos, & Patrão, 2010; Lawrence & Goodnow, 2011). Drake and Lawrence (2000) argue a distribution based on needs rather than equality reflects a view that the need is authentic and permanent and that the additional resources will positively impact the recipient’s quality of life.

In the 2012 national statistics, approximately 668,000 people in Australia had an intellectual disability, and many have limitations in their “core” activities of daily living so they are significant users of disability support services (ABS, 2014). A widely accepted norm is that all people are entitled to a decent life, regardless of ability. Where the general expectation is for adult children to be self-sufficient, parents of adult children with an intellectual disability currently face significant challenges in planning, facilitating and funding their care as adults in a context of individualised funding under the NDIS, and paying for care and guardianship arrangements. The increased life expectancy of people with intellectual disability (Bigby, 2008) means they are now more likely to outlive their carers (Bigby, 1996) than was the case a generation ago. When making a will, many parents seek ways to replace the care they have provided. Despite these significant and specific challenges, the will-making experiences of these families are largely absent from inheritance and disability literatures (Groce, London, & Stein, 2014).

Parents often include a calculation of the value and sufficiency of the Disability Support Pension (DSP) in determining any distribution. Previously, legal professionals often advised parents to disinherit their adult child with an intellectual disability and instead to leave their assets to siblings or other family members with the moral, but not legal expectation that these
beneficiaries would contribute resources towards the adult child’s care (Harp, 1997; McMullen, 1999). However, the risks of such an approach are obvious.

A perception of inadequate provision may lead to disputes; not only damaging to family relationships and resources, but potentially culminating in the judicial redistribution of assets (NSW Law Reform Commission, 2005). Will challenges by family members appear to be increasing (Greene, Fogler, & Gibson, 2012; McGregor-Lowndes & Hannah, 2009; Ryznar and Devaux 2013). When a child has an intellectual disability, a challenge to a will based on family provision legislation is likely to be bought by statutory Public Trustee officers who seek to ensure a person with such a disability receives a share designed to meet reasonable needs.

This article reports on the perceptions of 20 parents regarding the impact of the needs of their child with disability on their decision making in estate planning. The paper seeks to identify:

1. What principles, practices and intentions underpin asset allocation in wills in relation to family members with intellectual disability?
2. What are their plans for who should manage assets, lifestyle and care decisions in the future for and with an adult child with an intellectual disability?

Methodology

This research was part of a mixed method, research project exploring the prevalence, practices and challenges in will making and will contestation in contemporary Australia (Tilse et al., 2015a). Stage three of the project explored in depth, will-making norms and practices within families facing particular challenges. The families sampled in these interviews included step/blended families, families with cultural practices that may not align with assumptions underpinning family provision legislation (Wilson, Rosenman, White, Tilse, & Feeney, 2016) and families with a child with intellectual disability. This paper reports on interviews with 20 parents of adult children with this disability exploring the decisions made regarding planned distribution of family assets in their wills. Ethical clearance was obtained from the two universities involved in this study (UQ 2011001264 and QUT 1300000645).

Sampling and data collection

Interviews

A semi-structured interview schedule was developed from the literature and the analysis of stage one of this research – a national survey of will making practices and intentions. The schedule included demographic data, asset types, the adult child’s current and future needs particularly regarding accommodation, care and financial support, principles underpinning asset distribution within the family, the impact of disability on the process of decision making, current and potential future challenges and testator beliefs about securing their own future lifestyle versus inheritance bequests. Finally, respondents were invited to comment on issues perceived as important to will making in the context of having an adult child with intellectual disability. All interviews were conducted by the same interviewer.

The purposive sampling strategy sought parents with an adult child with an intellectual disability who were willing to talk about their estate planning. Recruitment occurred through a community disability support agency, a larger independent state-wide disability support organisation and in response to a broader media recruitment campaign. Twenty participants took part in sixteen interviews in 2014–15. The interviews related to 17 children, one parent having two children with intellectual disability. Participants predominately came from metropolitan and regional locations in Queensland with one from NSW.

Face-to-face or telephone interviews were arranged with participants who provided written or verbal consent recorded at interview. Interviews were digitally recorded and transcribed by a third party with transcripts checked for accuracy by the interviewer. Table 1 summarises the characteristics of those interviewed.

Four of the interviews (4, 6, 9, 10) occurred with both parents of the adult child with disability. The 20 interviewees comprised 14 females and six males. All interviewed males were in long-term marital relationships. Two female interviewees identified as divorced (1, 5) and one as recently separated (12).

Participants’ ages ranged between 86 and 44 years with 67 years being the average and median age. All of these adult children received the DSP (because of their intellectual disability) and all but one respondent reported providing additional, often significant, financial support. All parents reported a comfortable level of assets, and in part this reinforced their desire to make a will and reflected a belief that these assets should benefit the family as a whole. The one adult child not receiving additional financial support lived in the family home. In addition to their intellectual disability, all respondents reported that their adult child experienced physical and/or mental health co-morbidities.

Table 2 summarises each adult child’s characteristics. The 17 adult children referred to by respondents were almost evenly divided in terms of gender. Their ages

| Adult Child Characteristics | Male | Female |
|----------------------------|------|--------|
| Age                        | 86   | 44     |
| Gender                     | M    | F      |
| Intellectual Disability    | Yes  | Yes    |
| Accommodation              | Yes  | Yes    |
| Care                        | Yes  | Yes    |
| Financial Support          | Yes  | Yes    |
| Physical Health            | Yes  | Yes    |
| Mental Health              | Yes  | Yes    |
| DSP                         | Yes  | Yes    |

Table 1: Characteristics of the Adult Child
ranged between 22 and 50 years, the average being 36 years. One adult child had three step siblings, others had at least one sibling. Six adult children lived with their parents in the family home, two were home owners (facilitated with parental financial support), four adult children lived in residential care, five adult children lived in supported public housing with support provided to those with a disability and one lived in general public housing. Thirteen adult children required 24-hour care, four adult children managed their self-care but required support with domestic chores, transport, administrative and financial management.

Management and analysis of data
Interview data was managed using NVivo software (QSR International, n.d.). Thematic and content coding (Braun & Clarke, 2013) were used to analyse interview data. Primary codes related to the nature of each adult child’s intellectual disability and their requirements for accommodation, care and financial support, family relationships, asset forms, principles informing decision making, triggers for will making and the influences of previous estate planning experiences. These codes were developed by the interviewer and checked by the first author.

Results
Overall aims in future planning
Interviewees were all linked to support services and most had been proactive in setting up financial and housing provision for their adult child after their death. All noted the complexity of decision making given the changing policy context with the introduction

| Interview ID | Gender | Age | Accommodation type | Care support | Siblings number |
|--------------|--------|-----|---------------------|--------------|----------------|
| 1            | F      | 68  | Divorced            | Yes          | Yes            |
| 2            | M      | 65  | Married             | Yes          | Yes            |
| 3            | F      | 69  | Married             | Yes          | Yes            |
| 4            | M      | 71  | Married             | Yes          | Yes            |
| 5            | F      | 55  | Divorced            | No Former will-maker | Yes |
| 6            | M      | 60  | Married             | Yes          | Yes            |
| 7            | F      | 59  | Married             | Yes          | Yes            |
| 8            | F      | 86  | Married             | Yes          | No             |
| 9            | M      | 76  | Married             | Yes          | Yes            |
| 10           | F      | 73  | Married             | Yes          | Yes            |
| 11           | F      | 66  | Married             | Yes          | Yes            |
| 12           | F      | 62  | Separated           | Yes          | Yes            |
| 13           | F      | 67  | Married             | Yes          | No             |
| 14           | F      | 44  | Married             | No           | n/a            |
| 15           | F      | 67  | Married             | Yes          | Yes            |
| 16           | M      | 83  | Married             | Yes          | Yes            |

Table 1. Parent participant characteristics.

Table 2. Adult child (with a cognitive disability): Characteristics, current accommodation, care, financial support and siblings.
of the NDIS, conflicting legal and/or financial advice and the difficulty of predicting or foreseeing the future for themselves, their child with a disability and their other children. Consequently, it was difficult to be confident of a stable policy future that could guide their decisions.

Universally, respondents reported that will-making was essential with the two respondents without current wills intending to prepare one. These two respondents were the youngest parents in the sample. All planned to leave an inheritance if possible but noted that they would balance this with achieving a quality lifestyle for themselves. However, for many, enhancing their own current lifestyle appeared aspirational, as they remained concerned about the implications this would have for what they could leave behind.

(It’s) not so much how much we’re spending, but also what’s going to happen to them, and – we’re always aware lifestyle revolves a lot around their disability, let’s put it that way … Like if we do spend – like if we just decided to go overseas, well, that’s cutting into what we could leave them [10]

The two blended families in particular considered how “family” money was distributed. For one respondent “fair and reasonable” was the guiding principle, though what that meant in terms of asset distribution could be complicated.

[As her parent], certainly I’m very concerned about how she’ll manage in the future. I don’t really know. I just – we’re just trying to be fair and reasonable, yes … a fairness to [husband’s] children as well. [10]

None of the parents in blended families knew if an ex-spouse had a will that made provision for their child with a disability.

All respondents aimed at achieving a quality, comfortable and independent future life for their adult child but not necessarily achieving this by giving their adult child equal shares with other children. An ongoing disability pension was also seen as reducing the care tasks and financial demands for siblings once parents had died.

In reality, we would allocate our assets equally between [the siblings], [but] our current will leaves nothing to [adult child with disability], and the reason for that was his qualification for significant benefits. [2]

… Disability pension, she’ll be on that for the rest of her life hopefully, or some sort, and her needs …; – will be catered for if something happens to us, I’m pretty sure, by Department of Communities or whatever, without [sibling] having anything to deal with it financially as well. [7]

Respondents often considered their financial contribution via a bequest as “topping up the pension” but only to a level that would retain the pension, and protecting eligibility for the linked accommodation, health and transport pension benefits.

She’s living with me … But, ultimately if I die she will need accommodation … I think that with the Disability Support Pension, and with the money I leave her, there will be enough … [to] provide her with the lifestyle that she wants.[1]

Parents’ planned distribution of assets

Around a third of these parents planned to, or had left equal shares to their children, another third intended to leave more to the child with disability and one-third intended to leave less. Allocation decisions were based on factors such as the child’s level of disability, the desired lifestyle for this child, predicted costs of meeting future care needs, the needs and financial position of other children and the commitment of these children to care for their sibling with a disability. All parents wished to maintain family harmony after their death and to preserve the DSP. They planned their affairs to achieve these outcomes and used different patterns of asset distribution to achieve their goals.

Leaving an equal distribution

Some of those parents who planned a distribution of equal shares between their children had fewer assets and/or had a large family, so that an equal share of their estate would not impact on eligibility for the Disability Pension.

When we’re both gone it’s divided up equally between the eight – the house and car, if we still have one, whatever else has to be sold. There’s money. Then there’s no conflict because each of them gets exactly the same [8]

Others with a bigger asset base were able to provide a “safety net” for the child with a disability through inter vivos transfers such as buying a unit and/or a considering a disability trust while still dividing their estates equally.

Some thought that since no one could see into the future, it was safer to rely on a principle of equality, so that all children had an equal share of resources for whatever the future held. However, one certainty was that their child with a disability would always have an income (DSP) and this could not be said for their other children. The extent to which the DSP was seen as providing an adequate lifestyle varied, though all but one participant currently subsidised their child on DSP to meet expenses such as health insurance, holidays or outings. Where no provision was made to leave more, participants hoped that siblings would help. One testator [15] made the point that the obvious needs of the adult
child would be met by the DSP, so there was no need to provide more than an equal share, and indeed that something extra might be “owed” to the adult child’s siblings.

So they have got an equal share. The reality too – and I think people forget this – is the years when they were growing up, those boys suffered because there was a family member with a disability [15].

Overall the overriding principles underpinning participants’ decisions to leave equal shares were equality, preserving family harmony and reducing the chance of contestation.

**Leaving more than equal shares**

Parents planning to leave more to their adult child, generally in the form of property or interest from a trust, aimed to achieve equity of outcomes in terms of lifestyles for their children, rather than equality of distribution at their death. Nevertheless, they still organised their affairs so that the adult child would retain the DSP. Most participants who were leaving unequal shares considered that this might create problems, and therefore sought to ensure that their other children supported their decision.

If I look at fairness, my middle child has probably had an inheritance. She went overseas to study and that was paid for … there’s been a conversation with my younger daughter too – she’s OK [5]

For these parents, account was taken of past *intervivos* transfers to other children and the capacity of these children to earn an income and hence meet their needs. This group held the view that other surviving siblings or their descendants would eventually get any capital assets that were left to their child with a disability on the death of that child, and that their responsibility now was to meet current needs.

I suppose it is based on those who need it get it and really, that’s the way I’ve developed my will. [12]

Almost all parents in this group noted that generally the ideal distribution was an equal one but that in their family situation meeting the needs of the child with disability had priority and this may result in an unequal distribution.

We’re giving more to A because she does not have the capacity to earn money that her brother B has. C does need a little more to see her through, because she is a bit younger and her needs are greater. Normally it would be split evenly [2]

However, a concern for some parents who had planned to leave property, or a significant sum to that adult child was how it would be handed down to other siblings if the child could not make a will.

(She) can’t make a will. What happens to the proceeds if something happens to her? I mean, I’m not sure that we’ve got it really nailed down [7]

**Planning to exclude or leave less**

Some who excluded or planned only small bequests to their adult child with a disability considered that the state would meet basic living costs, or other siblings needed the money more, or that they would make more use of it. The principles underpinning these decisions were the needs or deservingness of other siblings and that the state would provide a living for the adult with disability that was not available to other children.

Because of [adult child’s] disability and because of his need to qualify for benefits, we think it in his best interests, and [sibling’s] best interests that he continue to qualify for that, to the maximum he possibly could. That drove the decision that’s reflected in our present will. [2]

Others making this decision relied on siblings to look after the adult child’s needs. It is notable that all but one of the parents interviewed were making regular financial contributions to “top up” the pension. One was considering reviewing their will to ensure that this could continue after their death.

I’m looking at certain conditions going on but not necessarily in the will. You can have a memo of understanding or something? [9]

This respondent also reported greater provision to the adult child’s siblings based on the belief their needs were greater than the adult child with a disability.

I don’t believe that [adult child] needs as much as the others do, because she couldn’t spend it. That’s the whole issue and it’s silly to have it sitting in a bucket and no one touching it until she dies. [9]

In almost all cases where parents were leaving unequal shares that did not favour their child with a disability, they understood that their decisions may lead to challenges from the statutory authorities to be dealt with, if necessary, by other family members. One participant was largely concerned not only about a change in the distribution, but also that the assets might pass out of the family.

That’s (contestation) not what we really want, but if it has to happen well I suppose that’s what’s going to happen [7]
These parents left little or less to their adult child to maintain eligibility for the DSP, to preserve family assets or believing that the adult child had less need for money than their siblings. There is a clear belief among all families that they, and not the state, should be in control of these decisions that they should work out what will suit the family, and not necessarily prioritise the needs of the adult child with disability.

**Summary**

Parents who planned to leave equal shares reflected the view of the dominant group in the prevalence survey (Tilse et al., 2015a), namely that all children should be treated equally. These parents generally could achieve equal shares without putting eligibility for the DSP in doubt, as the income level derived from it would not affect the child’s pension. Alternatively, they could afford to set up a disability trust with the child’s equal share. Such a trust is not assessed as part of the assets or income tests for the DSP.

Parents who were deciding on a greater share for their adult child with a disability did so in the context of the needs and resources of other children, and what they considered was a quality lifestyle for their adult child. The driving principles were equity and need, taking the assets used for other siblings into account, and the capacity of these siblings to earn a living. Parents who planned to exclude or leave less to their adult child were aware of the disability-related needs, but they considered that a child with a disability may need less money than their siblings, and/or that these needs could be met with the DSP. Their interpretation of the needs of the adult child and a belief that siblings or services would step in when needed guided these decisions.

**Influences on estate planning**

**Experience and advice**

All but one will-maker said that having a child with an intellectual disability was a major factor in their planning, generally making the whole process more complicated. Most commonly respondents reported their planning and distribution practices were influenced by their own and other’s family experiences.

The thing is that my father, [was one of] four children, his parents left everything to the eldest and the youngest. My father was in the middle, so it was always a bone of contention with him … which probably hurts a little bit. [7]

A friend’s husband died suddenly … then the Department […] stepped in and said, no, that they had to take the money out of the estate and it had to be in the daughter’s name. The daughter didn’t have much capacity to manage it … [the] money put into her name. So that made us aware that we have to do the same thing, and that we’re not sure whether we’ve done it right. Someone said that it can still be contested, even though it’s what we put in place. [7]

Several respondents reported that professionals, solicitors and accountants influenced their will making practices. This influence may result in a greater than equal share for the adult child.

I believe no matter what they’ve done or even if … they might not be the most wonderful child but they would get equal shares. I guess in this instance the solicitor advised that maybe a little bit more should go to [adult child] to suit her level of need. We were swayed to do that. [3]

Alternatively, it may lead to the adult child being excluded.

The solicitor said … “Well, [adult child’s] getting a Disability Pension and you don’t want to jeopardise that … Well, if you leave the majority to [sibling], she can always top [adult child] up.” [4]

**Planning for estate challenges**

Respondents unanimously believed it necessary to make a will. Yet the majority of respondents raised concerns about the adequacy of their wills when they were executed. Respondents outlined difficulty in sourcing quality professional, legal and financial guidance combined with knowledge and understanding of the complexity brought about by disability. The cost of accessing professionals was a further concern for respondents.

But I would perhaps like more guidance in how to ensure that we do the right thing [WM11]

I guess what would be lovely to have is a list of legal people or financial people … to be confident that [the will] would be drawn up and that it didn’t come unstuck at that eleventh hour. [WM13]

It’s very, very difficult to get quality advice and it is expensive. Our will cost us a fortune. I was shocked. … It was in the thousands. [WM12]

It’s been very, very difficult. We still don’t know. As I said, we’ll have to go and see another solicitor, and I know it will be ultimately our decision. But we’d like to know all the ramifications before we do that [4]

Most respondents had considered the possibility their will may be open to challenge by statutory authorities. Generally, respondents voiced little concern for challenges by the adult child’s siblings.

I can’t see [sibling] challenging it. It’s made me think that it would be good to discuss it with [him], I think,
so that he understands and doesn’t get a big surprise later. [3]

[Sibling] came with us to the solicitor. We wanted her to be aware of what we want and what’s happening … . So, she’s aware of everything that we say, or all our - what our goals and what our ambitions are, for [adult child]. Because she sees it as part of her - her family life, you know? [4]

Although respondents voiced openness in communication and transparency in their will making practices among immediate family members as beneficiaries, mixed comments emerged regarding family members actual knowledge of the will content – for example one respondent stated family were ‘aware of the spirit of the will but not details’ [12].

Family relationships such as with former partners and step family members, were a concern for some respondents regarding potential will challenges.

Because I have an ex-husband, I really wanted to make sure that the money was tied up, that [adult child] got it and if something happened to [her], it went to the boys. That there was no way that [ex-husband] could challenge it. [1]

Between the girls? I doubt there would be. [Sibling] does acknowledge that she’s already had quite a bit [financial support]. They very much acknowledge the situation. They’re very close … My worry more is the partners. [2]

Several respondents, aware of the possibility of will challenges by some family members or the Public Trustee, attempted to plan to prevent this occurring. However, one respondent, who recognised the possibility of a statutory challenge to a will that excluded their adult child, considered that their decision needed to stand to protect an adult child’s government entitlements even though it might cause difficulties for others.

So we decided to leave nothing to (adult child), run the risk of the adult guardian (sic) challenging our wills … and leave it in the hands of our daughter to manage [3]

Preserving entitlements to state support
Regardless of their financial status, for all respondents the major consideration was to maintain their adult child’s eligibility for the DSP. There were two approaches to achieving this aim: leave nothing or little to the adult child and rely on siblings who were beneficiaries to assist or leave funds in a trust set up in such a way that it did not impact on pension eligibility.

Equitable between three children, but A’s is to go into a trust and the trustees are to be the two boys and the solicitor [15].

These families clearly thought the state, rather than their estate, should provide a basic income during the lifetime of their adult child in the form of the DSP. Almost all were supplementing the pension but not all planned to ensure this continued after their death. While some expressed concern that children would not necessarily make the same informal provision as they had, they felt the options available were not appropriate – they did not see their child with a disability would be in a position to make decisions, or that they did not see setting funds aside was the most productive use of their assets. They expressed the view that the family, not the state, should be the primary decision maker about asset transfers and asset use. However, by not making adequate provision in their wills they were aware that the state, rather than the family, might have the last word in how assets were distributed and in having oversight of how the assets were managed.

Many of the parents while understanding the role of the state in relation to guardianship and protecting the rights of the person with an intellectual disability planned to circumvent its involvement. Despite this, all the families continued strategies to ensure the continued involvement of the state in the provision of income support, services and care.

Planning for ongoing asset management, care and lifestyle decisions
In addition to securing the financial future for their adult child, parents sought to make ongoing provision for support with asset management, care and lifestyle decisions. These parents not only considered how to distribute assets but also who would or could make decisions for their adult child in the absence of the parent.

For 11 families, decisions had been made in relation to accommodation with their child placed in residential care (four adult children), public housing (five), or as home owners (two). The remaining six children living with their parents required more consideration in relation to provisions in their parents’ wills.

Families who set up trusts had the most detailed plans. Four of the respondents were setting up trusts to manage the future care of their adult child. Several other respondents had an interest in setting up a trust, though they realised trusts required management.

We basically went, “We’ve got an accountant, we’ve got a solicitor, and we’ve got [sibling].”

The accountant’s got the [social security] laws, tax laws, the solicitor’s got the legal side of things, and [sibling] got R’s best interest. He’s the heart as well as the two brains on either side. [6]

Many respondents found current and future guardianship of their adult child a difficult issue. No participant mentioned being appointed as a guardian for their
child by the relevant Tribunal, and most commented on the difficulties of being an “informal” decision maker, that is acting on behalf of their child but without formal legal power to do so being granted after the child turned 18.

We’re informal guardians of A because I’m not prepared to go to complete guardianship. There’s been so much said about the problems of it – being the informal guardian is a recognised thing, to an extent. Everyone’s, that’s all right. You can just go to the bank and open an account. You say, “But no, you can’t” [9]

In part this lack of formality related to disquiet about the demands it would place on them.

A committee member with an adult child, he’s at the Supreme Court at the moment trying to get out of guardianship because of the issues of having to go through the audit function each year … He’s just had enough of it. There’s two of them on the committee that’ve got official guardianship and both of them say, “We wish we never did it.” [9]

They recognised that the informal arrangements they had set up may not ‘work’ for siblings but were not aware of how to set up alternate arrangements.

It concerns me that when we go, the boys will have to go through all the things that we’ve gone through with (Department), with (private) health insurance … (they say things like) “We can’t understand why she can’t do things” [9]

I have not looked into guardianship. I am [adult child’s] guardian and I do believe that when I pass away it will be [sibling who is adult’s child’s carer], but I’m not 100 per cent sure of that, that’s an unanswered question [12]

Some expressed concerns about guardianship but had found it difficult to get straightforward advice.

We went back [to the solicitor], because there were questions about guardianship as to whether we needed to go through that process. We were advised we didn’t need to, because we’ve always been her primary carer.

While there are clear processes for setting up guardianship arrangements around finances and lifestyle once children with intellectual disability turn 18, these parents had chosen not to use them, relying instead on the authority they had had as the parents of minors. They did not welcome what was seen as “state” intervention in family matters. They expressed considerable disquiet about the situation but overall hoped that siblings would be able to “manage” without a clear legal mandate.

Provisioning for the adult child generally related to activities of daily living, such as having stable, affordable accommodation, meals, clothing, health care, social activities, transport and holidays. Some families had arranged long-term accommodation either through organising social housing or residential care, or the purchase of a unit. Some had set up trusts to be managed by family or legal advisors. To varying degrees they had included siblings in discussions about their wills and discussed expectations in terms of future care. However, they had not made formal arrangements around guardianship, mistrusting the state procedures as too onerous, and acknowledged that their children would have to set up their own semi-formal or informal arrangements when they undertook responsibility for their sibling with a disability.

Discussion

Parents of a child with intellectual disability had much in common with other parental will-makers in their views of wills as a family concern and their intention to leave inheritances for their children, to maintain family harmony and to avoid will contestation (Tilse et al., 2015a). This group differed, however, in being more willing to consider leaving unequal shares to children considering need and equity as well as equality and in viewing wills as serving a wider purpose than asset transfers. Respondents commonly reported relying on “equity of outcomes” rather than equality in asset distribution when the total support provided to their adult child and their children without a disability was considered. For example, they noted that the adult child’s siblings often received support with education, career development and accommodation, especially in relation to marriage and the next generation. These responses contrast to the views reported in the wider prevalence study (Tilse et al., 2015a), where generally prior support to children was not considered in asset distribution in making a will. Need became the overriding principle for making provision for all children when balancing the adult child’s support needs with their siblings’ needs. All parents perceived that the need was ongoing but varied according to the extent to they considered whether and how additional resources from a bequest would positively impact on the recipient’s quality of life.

Parents were not directly asked, and it is difficult to draw conclusions from the data about how they viewed their child with a disability. These parents recognised that someone would have to replace them in providing co-ordination and care and they hoped this would be siblings. They had all given the matter considerable thought and were prepared to modify plans with changing service provisions with the goal of maintaining family cohesion.

These parents also differed from the wider population in considering the impact of the life time support for their child in the form of the DSP. The DSP was
perceived as a right, and in some cases was seen as obviating or reducing the need to provide from family assets. These parents were very conscious of the potential impact of an inheritance on eligibility for ongoing income support, health care, accommodation and transport linked to the DSP and prioritised maintaining their adult child’s eligibility.

The introduction of the NDIS, with individual funding and consumer-directed care, has added to the complexity of planning for the future for these parents. Access to specialised information on this newly introduced policy and service system change was variable at the time they were interviewed. As ageing parents, current changes in aged care policies, with a stronger focus on paying for care, also challenged them to consider the type and value of assets left for an inheritance once their own future care needs were met. There is a strong sense of parents trying to plan in the face of uncertainty, of relying on family solidarity for care of their child but finding little support for this in legislative and care systems.

Limitations

This study is based on a relatively small group of participants already known to service agencies. They were long term users of disability support services, relatively well informed about the changing policies and aware that significant changes were coming. They were largely planners with wills and enduring documents, and in some cases had established trusts. However, there was a considerable range of income and asset levels, intentions and strategies. The strength of the in-depth study is that it does demonstrate the complexity of will making for these parents and the diversity of influences and decisions.

Conclusion

There are profound changes underway in how services are provided that emphasise the individual rights of all people with disability, their entitlement to choice and control in their lives, and the requirement that they do not suffer discrimination. Parents of adult children with intellectual disability interviewed for this research highlight the range of ways in which they understood these rights and consequently the range of views about what is “fair and reasonable” in terms of an inheritance and the child’s quality of life after their death. In contrast with findings (Tilse et al., 2015b) that parents generally emphasised equality in the distribution of assets to children in a will, these parents were more likely to consider equity of outcomes for their children taking access to state services such as social housing and the DSP into account. This reasoning resulted in a range of practices in terms of shares in family estates.

The literature is largely silent on the experiences of these parents as they decide how to distribute assets after their death. It is clear that parents experience the tensions in the interaction of family provision legislation, adult guardianship legislation, rights in relation to the DSP, family principles around asset distribution, and an evolving care system that focuses on individuals and not families. They currently negotiate these with little support from legal or care service staff. They agree that asset distribution via wills is a family matter and resist state efforts to safeguard the rights of those with intellectual disability.

Consideration of what is “fair and reasonable” is contested within families, between the family and care systems and between the family, the state and law. The participants in this study demonstrate the difficulty of future planning in the context of ambiguity and change in service systems, different perceptions of need and entitlement and limited specialised advice. The NDIS that places responsibility for articulating needs and organising support on individuals and families rather than services, is likely to add to the complexity of estate and care planning. These challenges are also likely to be magnified in families where there are cultural expectations about division of assets, a history of family conflict, limited understanding of relevant laws and/or limited contact with service providers. These families had strong links to care services, but the future of these services post NDIS was not known.

While there is a broad agreement in Australia about how assets should be shared in wills, it is clear that having a child with ongoing needs for care and support can challenge the broad notion of “equal shares” and highlights a range of views about the desired quality of life for people with an intellectual disability. Article 12 of the UN Convention of the Rights of Persons with Disabilities (CRPD) cites the right to own and inherit property. Given the link between inheritance, poverty and disability (Groce et al., 2014), how this right to inherit is enacted in current practices requires greater attention in policy, research and practice.

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