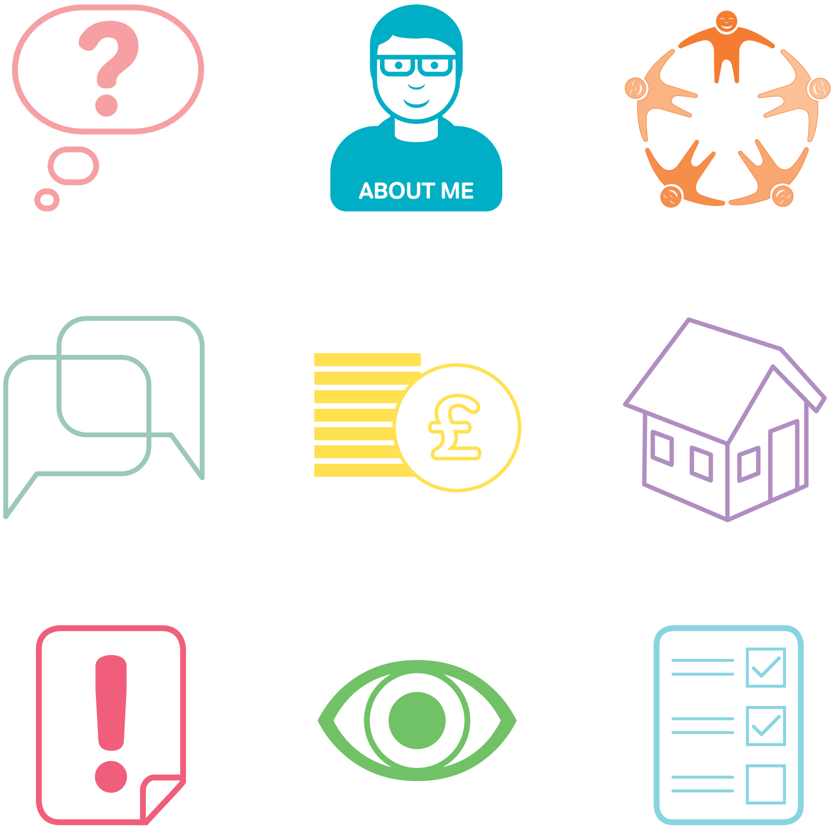
Thinking Ahead

Improving support for people with learning disabilities and their families to plan for the future



Christine Towers

foundation for
people with
learning disabilities

For My Daughter

And you Suzie, what should I leave you?
Not the pewter statue of the boy
his right hand missing,
let him stay on the mantelpiece
for the second hand dealers.
Not photos of my mother who died
before you were born into that grieving time.
Not money, to be banked for you
by someone else.
Not my poems, you'll never read them.
But the very fiercest of watchdogs
who wouldn't sleep for a hundred years.

Jo Roach

Published in Oxford Poets: An Anthology (2007)

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Contents

Workshop with family carers in Westminster.

Foreword

'What you leave behind is not what is engraved in stone monuments, but what is woven into the lives of others.' So wrote Pericles nearly 800 years ago. Of course, in Ancient Athens, disabled people died young. Indeed, they were often invisible in a society where physical fitness and family status largely determined your value to state and community. Thinking of ancient Athens may seem a very curious way to begin a foreword about *'thinking ahead'.* But amongst the many monuments in Athens, I remember a gravestone, a memorial to a girl called Athene. Athene was disabled but her parents had inscribed that she *'loved life and life loved her, death taking her whilst we, her parents, could still protect her'.* As I am a parent of an adult son with a learning disability, Athene's epitaph struck a chord in my own heart. Eight centuries on, many parents also share that fear about *'what will happen when we're gone'.* We are of course more fortunate than Athene's parents for we are probably the first generation whose disabled children will outlive us. And, if we use the rich resources and sound advice in the *Thinking Ahead* planning guide, we can ensure that our sons and daughters do have a future.

Thinking Ahead could not have been published at a better time than now. Living as we do in an age of austerity, planning ahead is vital for all of us as citizens and as family carers. Planning ahead is also essential because, notwithstanding the economic downturn, expectations of a fulfilling life for people with a learning disability have changed dramatically over the past decade. Those of us who are family carers have celebrated our sons and daughters gaining a level of quality in adult life which seemed unachievable when they were born. But progress has sometimes come with a high price. As Jean Willson so eloquently reminds us in her 'think-piece' at the end of this guide, we parents have been able to achieve so much on behalf of our sons and daughters because we have learnt from an early age to be the champions, confidantes and creators of our children's future. But we also have to remember the old truism that there is built-in obsolescence in all good parenting! In effect, we must also accept the personal challenge of succession planning.

Most of us will go through many transitions in our lives. Our adult children are no different and *Thinking Ahead* offers us a blueprint for managing those transitions well, with check-lists, practical advice and a toolkit to face what is all too often seen as an abyss by anxious families. I hope the guide will also be read by the commissioners, managers and providers of support for people with learning (and other) disabilities and their families. Adult life for our children will always be challenging (whether or not they are disabled), but we can ensure that we and they make best sense of the options and opportunities, and as Pericles wisely said, ensure that we do indeed 'weave our life with others', building and using the peer and community supports that are out there, even in these hard times, to help us.

Dame Philippa Russell
Chair of the Standing Commission on Carers

Why Thinking Ahead?

Over the years, parents of people with learning disabilities have said to us that concern about what will happen when they are no longer able to care for them is so great that they have considered taking their son/daughter's life before this happens. Many of them say that the first thing they think about every morning is what is going to happen 'when I'm gone'. This worry starts from the time when they receive their child's diagnosis and they know that their caring responsibilities will continue until either they die or their child dies. This lifetime of caring for someone with a disability creates a relationship that shapes family life over many decades.

'I think no other group of people in the world wishes their child to die before they do – but for parents of someone with high support needs it is very worrying that they will be left with no one to make sure they are happy, loved and cherished as full human beings.'

Adults with learning disabilities have a right to influence the direction of their adult life and be involved in discussions and decision-making, and parents and other family carers have a right to know about the options, their implications and how to make them happen. Yet there are no requirements for local authorities to provide support for planning for the future. In some local areas families may receive good support when they are beginning to look at the available options for leaving home for their relative with learning disabilities, but this is patchy. Most families have said that, after transition from children's services, they do not get another structured opportunity to discuss future options, which leaves them feeling it is their responsibility yet not knowing how to move things forward.

'I cannot stress enough how upset and worried I am about my daughter's future.'

When there is a lack of support to plan the future both adults with learning disabilities and family carers have to live with high levels of fear and anxiety. People with learning disabilities can be faced with making significant decisions or changes in their life, following the loss of a parent. This can increase the shock and trauma they experience, as well as lead to inappropriate placements.

'I am a widow, my son has no siblings. There will be no one around to look out for him when I am no longer able to do it or when I'm gone. I am only 61 but it is a constant worry to me and I get very anxious and upset about it. He is everything to me and to think he will be on his own breaks my heart.'

These are some of the issues that Thinking Ahead set out to highlight and to address through calling for changes in policy and practice and through the provision of a practical guide to support families to plan.

Background to Thinking Ahead

The increasing life expectancy of people with learning disabilities makes it imperative that families plan for the future. The number of people with learning disabilities over the age of 65 is predicted to double over the next two decades. The greatest increase in life expectancy will be amongst people with mild learning disabilities who will have a comparable life expectancy with people in the general population of a similar socio-economic group.

The fact that people with learning disabilities are now living much longer than they did in the past makes it more likely that they will outlive their parents, and the need to plan for a future without parental carers is therefore even more vital. Furthermore, it has been estimated that 60% of adults with learning disabilities are still living with their families. One third of these adults are living with a family carer aged 70 years or over (Department of Health, 2001), an estimated 29,000 people (Mencap, 2002). In 2011 there were an estimated 905,000 adults with learning disabilities in England (Emerson, 2012).

In the UK Government's White Paper 'Valuing People' (Department of Health, 2001) there was a recognition that older family carers needed to be better supported to make plans for the future, and as a result, many local areas allocated money from the Learning Disability Development Fund to provide initiatives to achieve this. However, this source of funding is no longer available and the work has lost momentum, leading to many older family carers feeling disillusioned and let down. Recent cuts in services and personal budgets, as well changes in the way local authorities have applied the Fair Access to Care Services eligibility criteria, have left some families feeling there is little support for them to be proactive in planning for their relative's life.

There is a significant gap in both policy and practice regarding responsibilities and guidance for supporting families to plan for the future. Although substantial resources have been allocated to developing policy and support at the time of transition from children's to adult services, there is little provision for people with learning disabilities planning their future during their adult lives, such as when they move away from the family home. Families describe a void after transition; they say it is 'a lottery' whether planning the future gets picked up again. Whilst family carers are sometimes viewed by professionals as being reluctant to let go, evidence from Thinking Ahead and other studies indicates that they would like regular input to support them to plan for the future, although this needs to be at a pace and at times that work for them.

Some families are reporting that the policy commitment to community-based support and personal budgets is leading to increased responsibility for arranging and delivering their relative's support. This is causing greater day-to-day pressure and thus giving them less time to make longer-term plans. This more individualised approach has the potential to make it easier for families to gradually shape the support and options open to their relatives after they leave the family home, giving a sense of continuity, and many families are already seeing the benefits of this. However, in order for this to be achieved, statutory authorities and other agencies need to give families up-to-date information and on-going help to understand and implement the options available.

The recommendations from Thinking Ahead aim to address the gaps in policy and practice thereby improving the support available to people with learning disabilities and their families to plan for the future.

Department of Health (2001) Valuing people: a new strategy for learning disability for the 21st century.

Mencap (2002) The Housing Timebomb; the housing crisis facing people with a learning disability and their older parents.

Emerson, E., et al. (2012), People with Learning Disabilities in England 2011.

Aims of Thinking Ahead

The aims for the Thinking Ahead project have been to:

- raise awareness of this issue amongst policy-makers, local authority managers in social care and housing, carers' organisations and more widely in the community;
- campaign for families to receive on-going and person-centred support to discuss and plan for the future;
- produce a practical guide that can be used by family carers, and those who support them, to make sustainable plans for the future.

Methodology

Phase 1

Fact finding to clarify the nature and extent of the issues and to inform our response

- A literature search was carried out to gather other research findings on planning with families and to identify what practical processes were already in place to help them plan for the future.
- Workshops were held with people with learning disabilities to gain their perspective at the start of the project as their voices have seldom been heard on this topic.
- Workshops were held with family carers (most of the participants were parents, although a small number of siblings were also involved).
- A national survey was conducted to gather quantitative and qualitative information, exploring families' personal experiences and what they would find most helpful. The results were generated from a sample size of over 300 parents with a son or daughter with learning disabilities aged 18 and over.

Phase 2

Responding to what had been learnt through developing a planning guide and campaigning for greater awareness and support for families to make plans

- A planning guide was drafted based on findings from the survey and workshops.
- Workshops were held to pilot the guide and measure the effectiveness of the design, layout and content to families.
- Discussions were held with individual family carers to discuss specific areas in more detail, particularly regarding the requirements of families whose relatives had more complex support needs.
- Professionals in community learning disability teams and carers' support services were consulted about how they could improve the information they offer to families regarding future planning and increase the opportunities for families to discuss relevant topics.

The Thinking Ahead Advisory Group contributed to the work at key points. The group had representatives from organisations with an interest and commitment to good family support. Some of these representatives were also family carers who brought additional expertise from their personal experiences.

Findings from the survey

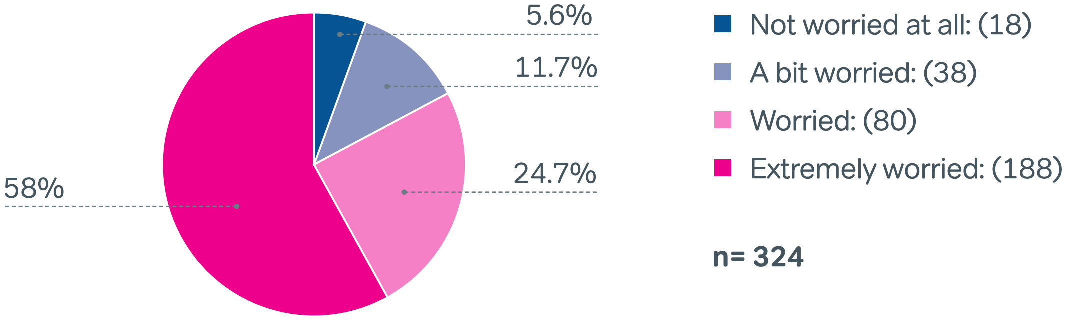
Key messages:

- parents have an extremely high level of anxiety and fear about the future;
- 85% were either 'worried' or 'very worried' regarding whether their son/daughter would get the support they need;
- parents have very little trust in 'the care system' to help them plan the future;
- professionals spend very little time talking with parents about future plans;
- parents feel it is a 'battle' to secure appropriate care and they often lose it;
- there is a lack of clear and accurate information to help with planning.

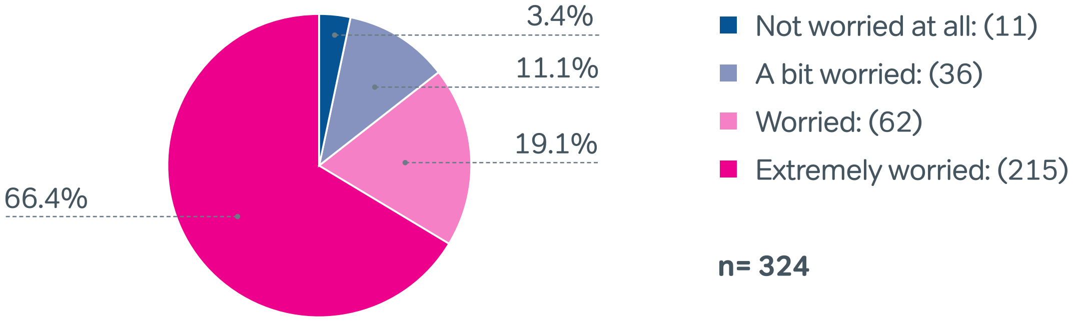
The survey asked questions to collect information on three main areas:

- **The level of worry that families experience about the future;**
- **How much help they have had with planning for a future when they are not around;**
- **What would help them to plan for the future.**

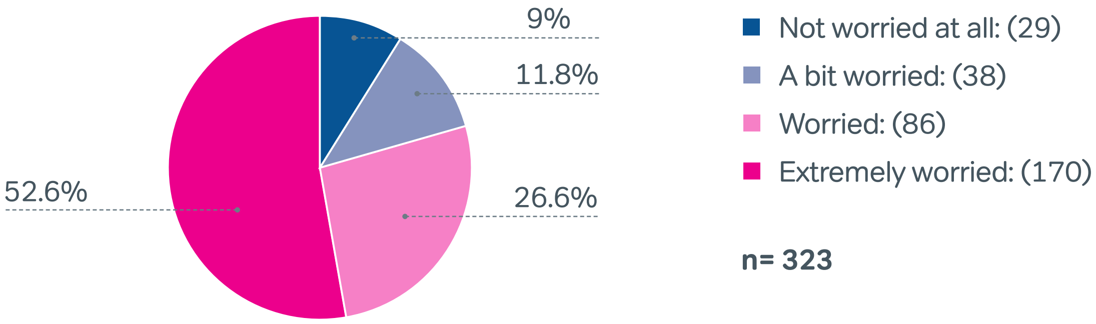
Will my son or daughter have a place to live where he/she is happy?



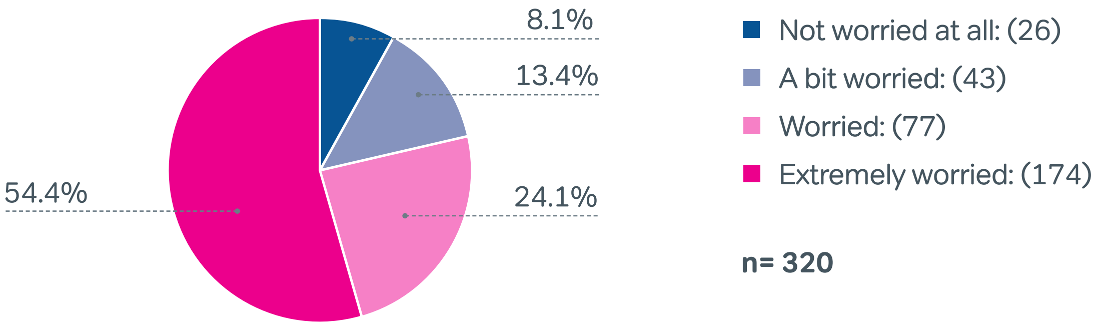
Will my son or daughter get the support he/she needs?



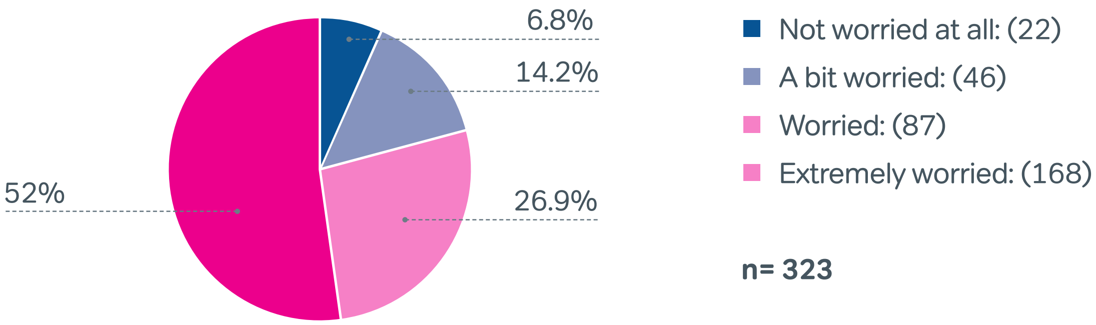
Will anyone speak up for my son or daughter to make sure he/she has a good life?



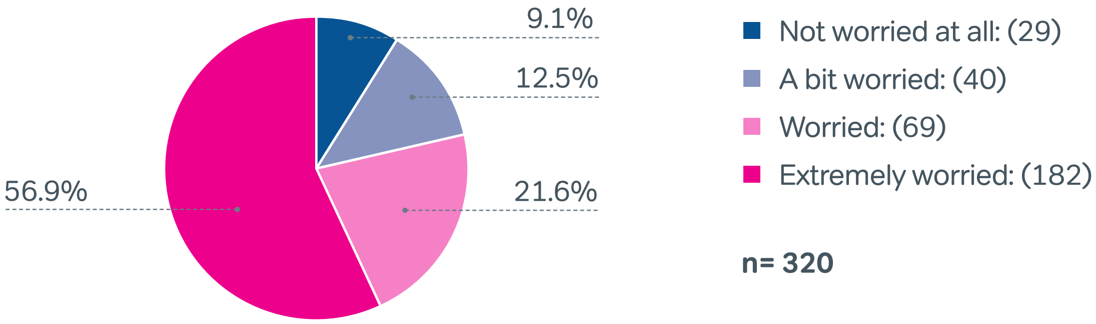
Will anyone help my son or daughter to make decisions that are in his/her best interest?



Will my son or daughter have friends and feel part of his/her local community?



Will anyone make sure my son or daughter is safe and well?

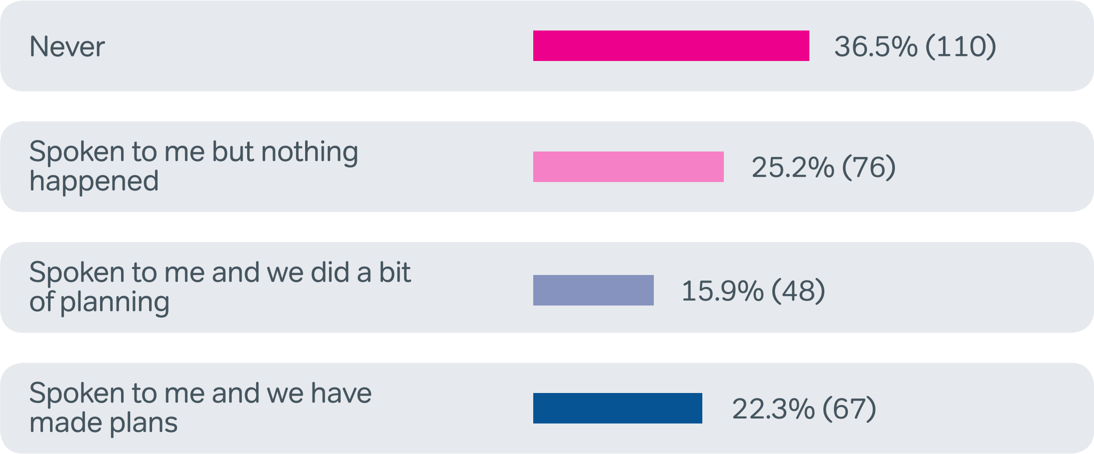


In the answers to all six aspects of worrying about the future the percentage that was either worried or extremely worried is either above or just below 80%. The highest percentages are for whether their son/daughter will have somewhere to live where they are happy and whether they will receive the support they need. It is unacceptable that parents live with this level of worry.

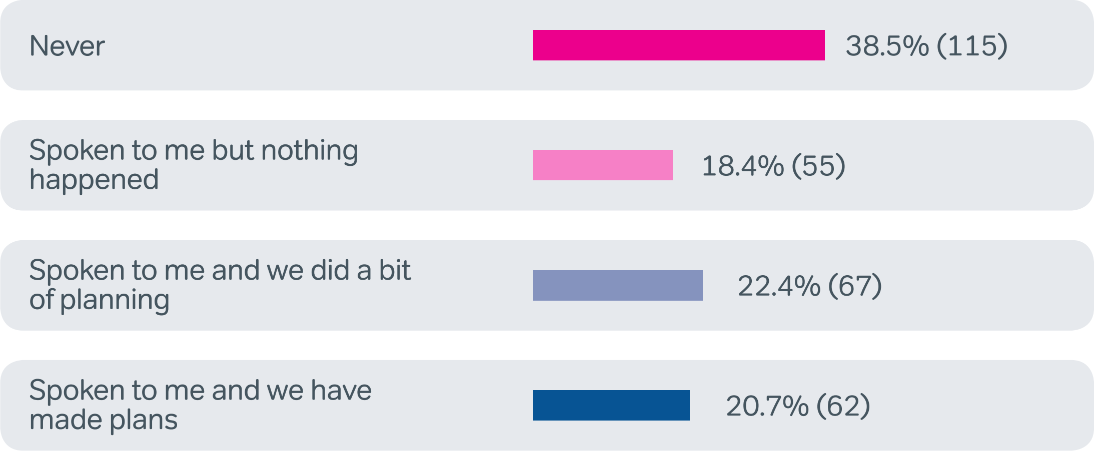
Participants were then asked whether someone had spoken to them or helped them look at these issues. The majority of parents said either nobody had or that they had had a conversation but nothing had happened subsequently. Only 38% had done some planning around where their son/daughter might live whilst 62% had never been spoken to by anyone or nothing had happened.

Has anyone ever spoken to you about, or helped you with, any of the following?

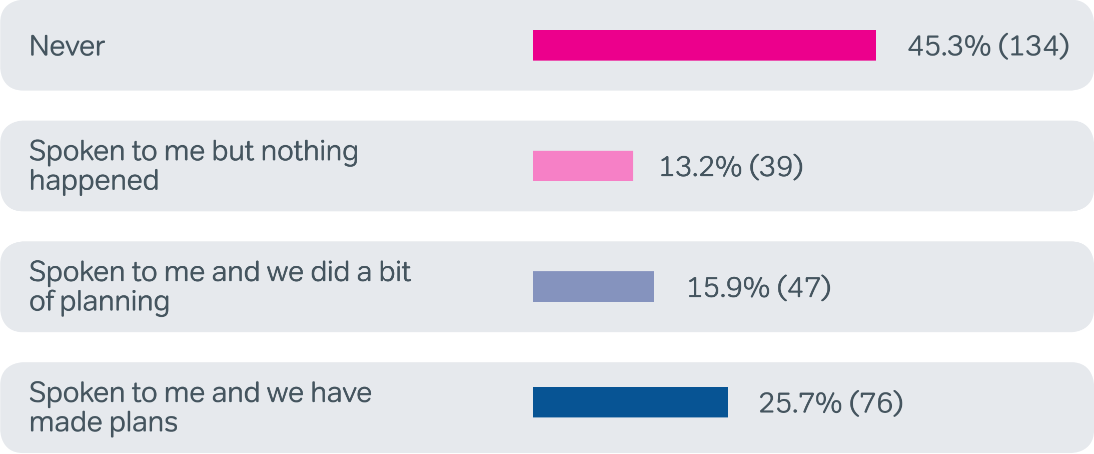
Whether you would like support to look at the options for where your son or daughter might live in the future (n = 301)



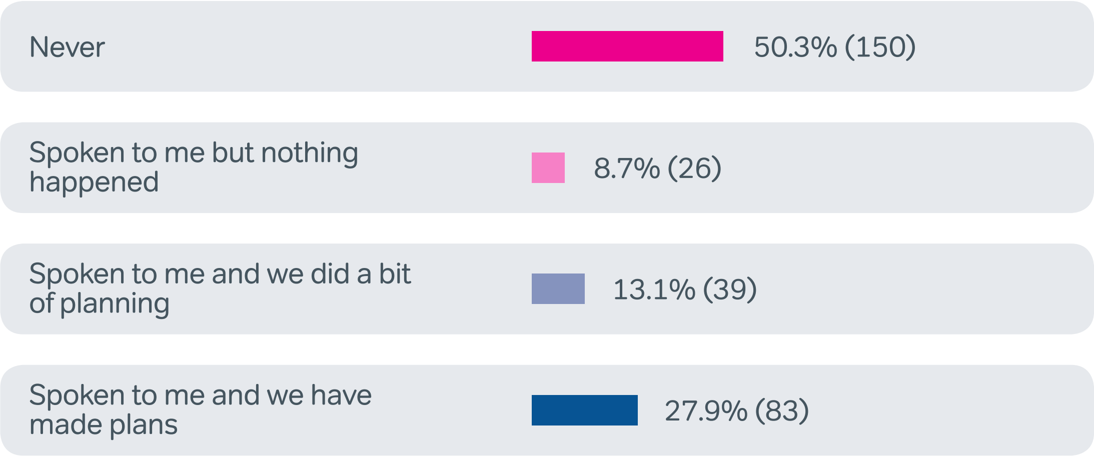
Making a person-centred plan that says, for example, who are the important people in your son or daughter's life, what helps them to keep safe and well (n = 299)



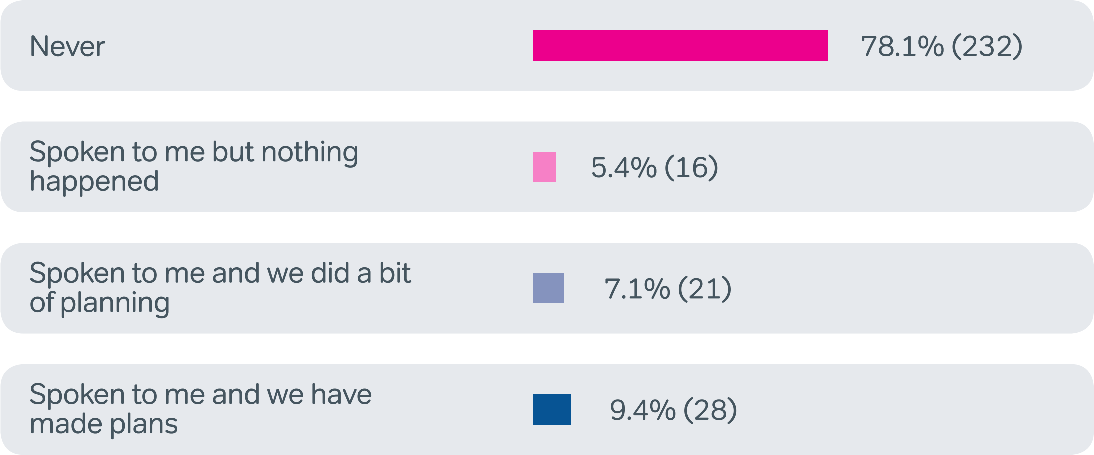
Where your son or daughter might stay or who might support them in an emergency (for example, if you suddenly had to go to hospital) (n = 296)



The ways in which you can leave money or property to your son or daughter (n = 298)



The ways in which you can leave memories for your son or daughter (for example, making a memory box, photo albums, life story book or family history book) (n = 297)



In answer to an open question at the end of this section, a mother said:

'In my experience, all the help has been in response to my requests for information – in other words, the help has to be actively sought out.'

Yet these questions are central to planning a good life and, on the whole, will lead to the development of sustainable and cost-effective solutions in the long term.

Where someone had spoken to families we asked who this had been (whether a family member, a practitioner or someone else). There was a variety of responses depending on the topic: social workers/care mangers were the main people to talk about housing, person-centred planning and emergency plans, and solicitors were the most likely people to have raised the topic of leaving money – either the family's own solicitor when they were making a will or a solicitor at a Mencap wills and trusts presentation.

At the end of the survey there was an open-ended question about what would be helpful, to which we received over 160 replies, including the following:

‘A simple reference book with key names and numbers.’

‘Have a formal/informal advocate to organise and speak for you.’

‘Information about power of attorney and appointees.’

‘Provide information about organisations such as Housing Options or Shared Ownership Homes.’

‘Mortgage lenders could offer loans and income support could pay the interest.’

‘Information on options – housing, support, advocacy, finances.... plus help with the emotional stress of thinking about it all!’

‘An independently resourced support group, available for each family, run by people with learning disabilities, parents, some professionals (if invited) allies and friends.’

‘Learning from the experience of other carers or someone who has lost parents and who can highlight all the issues that came up and what worked best for different scenarios.’

‘Government grants to parent/carer support charities so they can employ a broker to help families, set up carers’ days, produce materials in a range of media formats so carers can access suitable information to take them through the minefield.’

‘Regular national, regional and local webinars and workshops on wills, trusts, person-centred planning, support planning, housing options, how to form housing co-operatives/associations, sources of funding for housing co-operatives/associations.’

Findings from the workshops with people with learning disabilities

Key messages:

- too many restrictions are placed on our lives;
- people focus on our learning disability rather than our ability: it should be the other way round;
- if we are given more independence our confidence grows;
- we are underprepared to cope with loss and bereavement;
- friendships are important in helping to build self-esteem and a sense of safety;
- people need to talk to us about the future;
- we need to be involved in making plans that are then taken notice of.

The majority of the people who came to the workshops had mild or moderate learning disabilities, but because they all belonged to an advocacy group, they were used to speaking up for a wider group of individuals, including those with more complex needs.

Participants felt that too many restrictions were placed on their lives because the focus was on their learning disability rather than on what they could do. There was a fairly high level of agreement that they felt they were 'wrapped in cotton wool', which didn't necessarily help them to have the confidence and skills to cope when their parents were no longer around.

Participants said it was important to 'build our ability to cope with loss and bereavement' to prevent terrible feelings of loss when faced with the death of a parent. Some strong messages were:

'We need to be less protected.'

'We need to go to funerals.'

'We need our families to talk to us when people are really ill or dying.'

The workshops provided evidence that people with learning disabilities worry about their future. One man whose parents had died and was now living with his brother said how worried he was that his brother might not return from work one day:

'You never know what is around the corner.'

They also emphasised the importance of friendships in helping to build strength, self-esteem and a sense of safety as it was felt that those without good friends were more at risk from people pretending to be friends and taking advantage.

Most workshop participants felt they needed to think about what would happen before an emergency arose; as one participant said:

'Having a plan has put my mind at rest.'

But there was a strong emphasis on the need to go step by step, in their own time and for others to stick to the plan and not just 'leave it on a shelf' or ignore it.

Findings from the workshops with parents and siblings

Key messages:

- we feel the need to be protective of our sons/daughters because of our experiences over the years;
- trust in support services is an issue in making plans for the future;
- support from siblings is valuable but inconsistent;
- circles of support can be a lever for change but are difficult to instigate;
- person-centred planning is a vital practice;
- making an emergency plan is a good place to get started;
- there is a lack of information on housing and support options.

Barriers to planning

We began the workshops by asking family carers for their response to what people with learning disabilities had said about needing to be less protected. Family carers didn't disagree and explained: 'We need to be less protective but the world feels very unsafe.' They talked about the bullying and hate crime their relatives had experienced and the stories they had heard in the media, in particular the Winterbourne View scandal in June 2011, and from people they knew about mistreatment and poor-quality care. They also explained that the subject of the future is difficult to face as

'we're looking at a time when we are not here to protect and that is what we have done over the years'.

Families explained why it was difficult to face this issue: 'I'm worried that planning for the future may mean that my son has to leave the family home'.

'Planning the future means facing your own mortality – none of us want to do this.'

Family carers talked about the importance of trust and many referred to their experience at the time of their son/daughter's transition from children's to adult services:

'Our experience of planning at transition influences our trust in planning for a move away from home.'

Families talked about how difficult it was to know where to start as there were so many things to think about: 'It's hard to know what to do when you have a child who cannot tell you what they want… We don't know where the best places are to get the ball rolling.' One father explained what had jolted him into making some plans: 'I went to a meeting and there was an elderly couple there who were saying they didn't know what to do. It made me realise I didn't want that to happen to us so we made plans and now our daughter has her own place through a shared ownership scheme.'

Of huge concern was the poor quality of support: there was a consistent message that family carers do not feel confident that the people who would support their relative would have the appropriate attitude, knowledge or skills. They wanted support staff to have more training, better contracts with higher pay and good career options.

Involving others

When we talked about the role of siblings we found there was a range of views: 'We don't know how much to involve them'; 'We want to protect siblings – we don't know where they will end up living and how much they will be around.' Those who wanted siblings to be involved realised this was not a straightforward solution, especially with the current economic downturn and lack of social cohesion: 'Lots of people in our family are not in certain situations.' The families who found discussions about siblings most difficult were those who had an only child: 'It's hard when there are no siblings to watch over them.'

These concerns were apparent when we explored the idea of circles of support: 'I am quite isolated as a parent as my daughter does not like meeting new people, my husband has died and I have no other children.' Families were also unsure whom to ask to contribute to planning for the future because they did not know how to get people from a younger generation to be involved in their relative's life. However, circles were viewed as a lever for change:

'You could use a circle of support to introduce the topic of planning for the future. It shows us there are other people who will be there after we have died which is often hard to believe as a parent.'

What families said would help

Families understood the value of person-centred planning as a way of making a start and involving their relative: 'Person-centred planning lets our sons and daughters have a say in their future.' One family who knew they needed to support their daughter to move on from her family home said:

'A social worker suggested we look at one place but it was so awful it put us off doing anything more.'

When the idea of person-centred planning was suggested as a way of shaping what their daughter needed, the family could see a new way forward.

The idea of making an emergency plan was seen as a good place to start:

'Emergency plans are very important in making us parents feel at ease about the future.'

Many families were feeling let down by the lack of information on housing and support options. For a number of families this seemed to be crucial to their ability to move forward. Many parents, especially those over 60, were not aware of the differences between residential care and supported living; they did not know that supported living could provide 24-hour support, and that it was not just for people who were able to do many things for themselves. This lack of understanding made many family carers ask for residential care and they were upset that their relatives' needs were not being properly met when supported living was suggested.

'There continues to be a lack of service development, including housing options for disabled people.'

These comments confirmed our perception: for parents to feel empowered they need access to information and advice on the key questions to ask. Without it, they will have a limited ability to shape the future.

We asked families what they thought would help them to make the leap to begin planning for the future. The most frequently expressed comment was that they needed someone they could trust to support them over a number of years:

'Some families feel they already have too much going on. They don't want to take on any more; they need someone to come along and say "do you want me to take this on with you?"'

'It needs to be someone who knows the family, not a stranger coming in and saying "you need to plan".'

Workshop with family carers in Norwich.

Developing the planning guide

The planning guide was developed in response to what was learnt from talking to people with learning disabilities and their families. Parents had emphasised the emotional aspects of thinking about the future so the guide was written in a way that aimed to acknowledge and address this; to give encouragement and ideas but not to be prescriptive. 'The first hurdle everyone needs to be helped over is actually thinking about the future and all the emotional implications that can have.'

Because planning for the future is an emotional journey, the planning guide emphasises the need for people with learning disabilities and their families to have a support network that will be there to help. The responsibility for planning needs to be shared and families have to feel they can ask others to get involved. This support network would also be an investment for a possible future when the person's parents are no longer alive. It was clear that parents wanted to plan at various times in their son/daughter's adult life to put things in place as and when they were ready rather than be asked to 'make a plan' at one point. Families were looking for something that supported them to think about the future, possibly over many years. For this reason the guide aims to encourage families to prepare for the future at an earlier stage, rather than leaving it until they are older or in a crisis situation.

Families felt powerless because they did not know where to go for information or what they should be asking. The guide therefore includes lists of helpful publications and websites where families can obtain more information and it also suggests questions they can ask their local authorities or other organisations.

'More information about what is available or accessible and less red tape around the route that I, as a carer, can take to achieve this without reaching crisis point first!!!'

'Recent cuts, reductions in services leave me struggling to find who/where overall responsibility lies for his future welfare.'

The guide was piloted with individual family carers as well as a few carers' groups. As they were at various stages of planning the future, they commented from different perspectives; for example in some cases the relative had left home and in others families did not even feel ready to think about a move.

Overall, families appreciated the guide and the way it compiled vital information they felt they didn't have. A parent said:

'Now I know what I need to say or ask about when meeting my daughter's care manager. The different bits of the jigsaw are all in one place.'

A number of parents said they wished they had been given a guide like this at the transition from children's services so that they could have continued the planning process in their son/daughter's adult life. Michelle Mould, mother to Rosie who is 18 and has autism, and is involved in training the trainers in Early Support said:

'This planning guide could be very useful at transition… It would be something that I could recommend as a tool for professionals to share with families.'

However, some parents found it much harder to get going; they knew they needed to plan but felt so let down by services, especially since the recent cuts, that they found it hard to focus on the content of the guide. One mother said that she knew she needed to plan but her husband would not discuss it. She found this so hard that she decided not to meet again with the group. From the workshops it was evident that many parents will need the opportunity to talk about their past experiences, fears and hopes before they can begin to actively use the guide. They knew it might help but needed time and support before they would be ready to put things in place for the future.

One of the strongest findings from piloting the guide was that family carers needed support to think through the issues and begin to plan – it was not something they felt they could do on their own. The family carers who looked at the planning guide as part of a group felt it had been beneficial to discuss things together; they shared ideas and encouraged each other to take some steps. They also offered to help each other, for example by putting their names on each other's emergency plans or by joining a circle of support to help with planning. The workshops were run as a series in which different topics were introduced, such as planning in a person-centred way. Parents went away to discuss the topic with other family members and other people they were close to and returned the next time to share ideas or problem-solve together.

We also asked people working in care management teams, provider services and carers' organisations to look at the planning guide and held discussions with them about how they might use the guide within their work. There was general agreement that running local workshops to introduce families to the guide over a period of time, rather than at a one-off event, would be beneficial. Care managers suggested they could use individual sections to shape discussions with a family. In one area there was little information available about the local housing options even though parents had been asking for it for a long time. This prompted a discussion with commissioners about using the table in the guide to identify the appropriate local services that corresponded to the options described.

A number of care managers and health practitioners thought their review process should be amended to have a question that raised the topic of planning the future in order to identify whether this had been looked at and to find out what would be helpful. Also, they suggested that putting resources into Thinking Ahead would contribute to their prevention strategies through, for example, reducing crises, safeguarding incidences and referrals to mental health and bereavement services.

Sue and Paul Caldicott, parents of Anna, who lives in the family home

Sue: We are very worried and scared about where Anna will go when we're not around. She's always been with us without any respite and wherever we go to find out what options are available, there's never a definitive answer. It's so difficult to plan now for what is going to be there in the future because things change all the time.

Paul: As a dad, attending a group which was made up of just mums didn't bother me. Men are not always as understanding as women would be and Sue and I have always done everything together. In the meetings we've attended, it's usually been a mum on their own and it's hard enough with two of us. We're self-employed too and if we had 'proper jobs' we couldn't support Anna.

The Thinking Ahead carers groups have got us on the wagon. When it was first suggested to us we were nervous but it is because of that group that we've met lots of other carers. There's a bond there and everyone wants the same: we're all singing from the same hymn sheet. Having the planning guide in front of you makes you look and explore new options.

We've begun to put things in motion. We've never done a plan for Anna and never asked anyone for any help but the group showed us it was acceptable to reach out to others. Now people are keen to help and we've broadened our daughter's circle. We had never thought about making a plan or taking precautions for when we're not around.

The guide has helped us with thinking about what would be best for Anna.

We feel there is not so much support on offer because we've done such a good job by ourselves. Carers are getting older and are finding it harder to support their relatives, therefore people need to look at carers' situations more and be more certain about what help is out there. We'd love to be around to see what happens to our daughter as she's been with us all her life which maybe makes the prospect of the future more difficult.

Content of the planning guide

The planning guide has nine sections that take families through different aspects of thinking about and preparing for the future. Each section can stand alone so families can concentrate on the section or sections most relevant to them. However, many themes run through the different sections, such as the value of involving others in discussions and planning, reinforcing key messages. Although the guide has been written so families can use it independently of organisations and services, many will want or need support to think about options and move things forward.

The nine sections are:

1. Making decisions: information to help you understand the legislation and practice that relates to decision-making.
2. Making plans for the future in a person-centred way: an introduction to how person-centred planning can help you to think about what options might work well for your relative.
3. Building friendships and support networks: describes the benefits of having more people involved in your relative’s life and ideas for achieving this.
4. Talking about difficult subjects: ideas about how to talk about subjects that can be difficult to raise, such as growing older and death and dying, with your relative.
5. Making financial plans: an introduction to making a will, setting up a discretionary trust and power of attorney.
6. Housing and support: information about the different housing options for your relative and how to get the support they need.
7. Making a plan for emergencies: how to put together a plan that can support your relative to get the right support should you suddenly have an emergency.
8. Keeping an eye on things: how to ensure your relative has a good life and is well supported when they leave the family home.
9. Making a plan for the future: drawing together your ideas to make a plan for the future.

Copies of the planning guide are available from www.learningdisabilities.org.uk/thinkingahead

Jean Willson, mother of Victoria who lives in a supported living scheme

'Victoria's future is very uncertain at the moment as she is very ill but I have always had concerns about what will happen when I'm no longer here. I'm so busy being her champion, and I believe I'm the best, however, if her life must go on then all the things I've done must go on with it. I've got to pass the baton on and it's not easy. It's this champion role that's missing, things that parents do automatically like breathing, eating and drinking.

A group of people, not just one, are needed to take on this role, a group who will think similarly to me, will love and care for her, watch over her and look at things holistically like I do.

Meeting as part of the Thinking Ahead group has prompted family carers to really think about all the practical things that we know are there but have never thought about actioning. You must never do it later – you must do it now. All of this Thinking Ahead is going to be my last and final gift to my daughter and what a wonderful thing to do!

When I saw some of the work the project was doing I thought 'Yes, it will encapsulate that gift of independence and it will be done with love, will be practical and will be treasured.' And this is relevant not only for my family but for all families nationwide.

When I think about leaving Victoria in the current care system, I feel a bit anxious because things can change tomorrow. But if she's got her circle of friends and is armed with practical tools outlined in the guide she will be set on the right road to continue the way I've campaigned for her to do for the last few years. That gives you an enormous sense of comfort and it is reassuring to know that there are plans in place. It makes you less anxious and fearful about the future, reassures you that you've done your very best and, in doing so, have gained peace of mind. I believe that Thinking Ahead is an enormous resource for all the family to make plans for the future.

The guide itself acted as an aide-memoire to things I knew I had to think about. It's going to be a very practical checklist for parents as it is designed in such a way that you can go at your own pace, which is so beneficial for the diverse group of family carers as our time isn't ever our own.

I am continuing to secure a circle of champions for Victoria to ensure she has a healthy, happy and safe future. I've been training her sister and her friends to support her and, while in my head I know they will take over, we very rarely write it all down. It's down to the Thinking Ahead planning guide that we've written down all these action points and created a living legacy. I've done it all with love and I've never resented a moment of supporting my beautiful daughter. It's all been done with love.'

Piloting the planning guide in Norwich.

Recommendations

Summary of recommendations:

Policy and guidance on supporting people with learning disabilities and their families need to include statements on the importance of planning for the future, and requirements for local services to have a clear system to ensure future plans are developed.

Local authorities should make information about planning for the future available to families; this should include delivering an annual Thinking Ahead information day and a programme of workshops for families wanting to look at options and put things in place.

Housing and support options should be developed so that families know there are positive and safe options available when they plan for the future.

The importance of family, friendships, support networks and community connections should be recognised for the value they bring to people with learning disabilities and their families when planning the future.

These recommendations aim to address the gaps in policy and practice and thereby improve the support available to people with learning disabilities and their families to plan for the future.

To policy-makers:

- Ensure policy and guidance on supporting people with learning disabilities and their families include statements on the importance of planning for the future, and require local services to have a clear system for developing future plans. This needs to be given the same importance as planning transition from children's to adult services.
- Promote funding streams for family carers' support groups, peer support between families and generic carers' organisations, to ensure families have the information and support they need to take the steps to make plans with their relative with learning disabilities.
- Promote funding streams for advocacy organisations and other peer support groups for people with learning disabilities to discuss the future and develop ideas about what would work for them.
- Consider how housing policies can better meet the needs of people with learning disabilities to live in areas where they feel safe and where they have, or can build, meaningful friendships and community connections.

To local authorities:

- Have questions in their assessment, support planning and review processes that identify how a person with learning disabilities and their family carers would like to be given the support they need to plan the future.

- Organise a Thinking Ahead day each year to provide families with information and signpost them to support that is available (similar to the way in which many local authorities organise a transition event for people with learning disabilities and family carers).
- Introduce a rolling programme of workshops for people with learning disabilities and family carers to look at the different aspects of the Thinking Ahead guide in order to create a person-centred, workable and costed plan.
- Provide clear and up-to-date information for families about the housing and support options available locally.
- Provide housing options that not only put a roof over a person's head but also create a supportive network that helps to keep them safe and have meaningful connections with other people.
- Include in their carers' strategy the need to provide opportunities and support for family carers of people with learning disabilities to make plans for the future.

To practitioners in health and social care:

- Practitioners in learning disability teams to use opportunities to talk to people with learning disabilities and family carers about their plans for the future, including signposting them to information in the Thinking Ahead planning guide, so that families are being actively supported.
- GP practices to signpost patients who are family carers of people with learning disabilities to sources of support for thinking ahead and planning for the future.
- Involve siblings and other members of the extended family (with the permission of the person with learning disabilities) in processes such as reviews and support planning so that parents do not feel it is their sole responsibility.
- Ensure that shared decision-making with families and their relative on critical health issues, such as end of life plans, is seen as central to planning the future.

To the voluntary sector and provider services:

- Act as champions for the planning for the future ideas in Thinking Ahead through the provision of peer support groups for family carers and for people with learning disabilities, and through the production of materials and information on their websites and other media.

To families:

- Ask for an annual Thinking Ahead event and/or rolling programme of workshops to be set up in their local area so that family carers can meet to talk about the future and support each other in the planning process.
- Use the planning guide to initiate discussions with their relative with learning disabilities, with other family and friends and with professionals about establishing a plan for the future. Talk about ideas at annual reviews and other meetings.

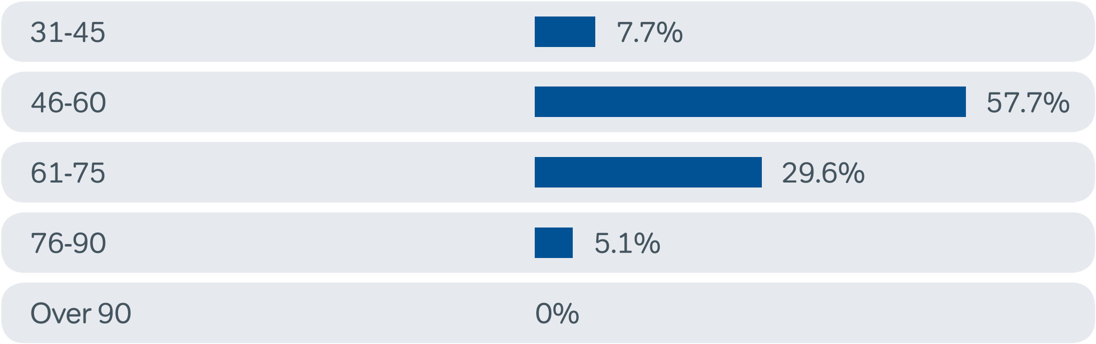
To people in local communities:

- Look for opportunities to become involved in the lives of people with learning disabilities by getting to know families, contributing to circles of support and helping them to build connections with other people.

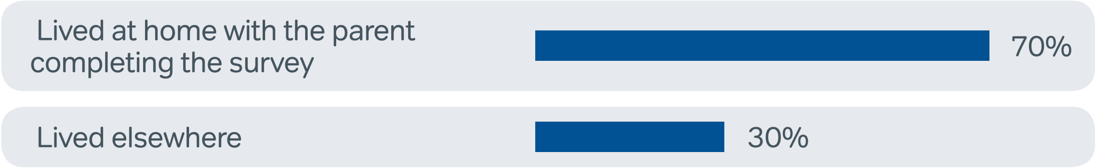
Appendix

Demographic information about the parents who took part in the survey

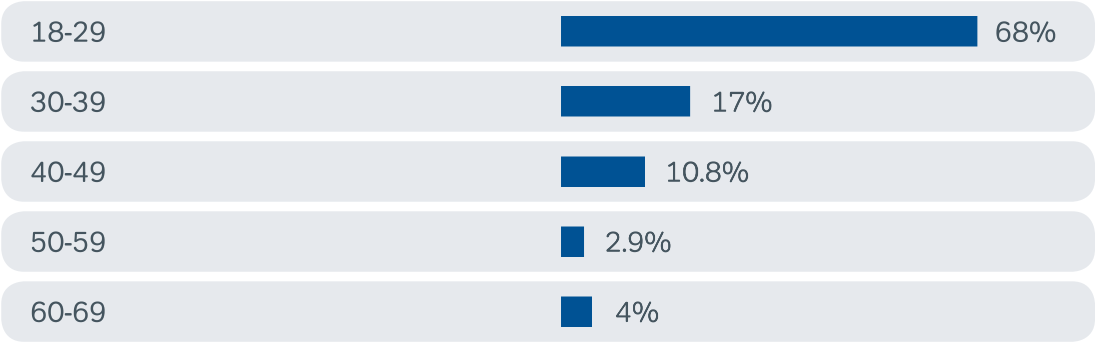
Age:



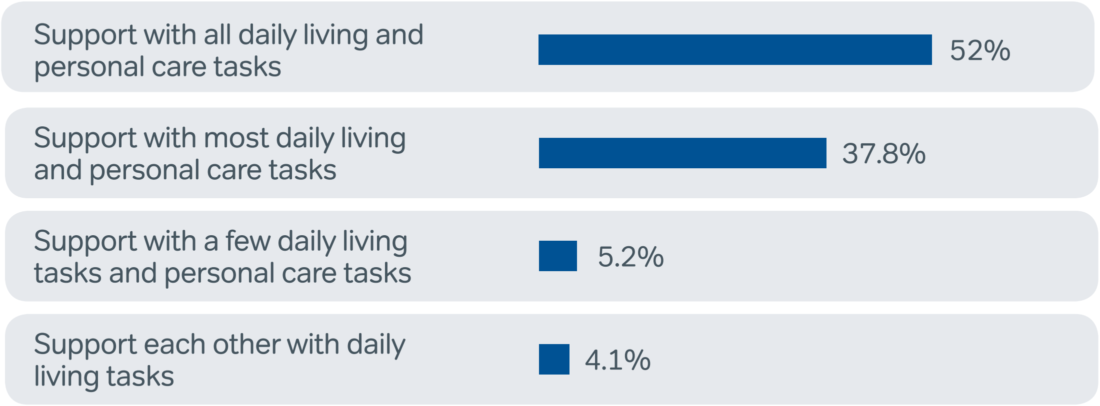
Where their son/daughter lived:



Age of their son/daughter:



Level of support their son/daughter needed:



Where participants lived:

Over 90% of parents lived in England and a small percentage in Scotland, Wales and Northern Ireland.

Thinking Ahead: a planning guide for families is available from www.learningdisabilities.org.uk/thinkingahead

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