A SENSE CAMPAIGN

sense
connecting sight, sound and life

When I'm Gone

Securing long-term care and support for disabled adults

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Foreword

Gillian Morbey
Chief Executive of Sense and
Sense International

For 60 years, Sense has provided support to disabled people with complex communication needs and their families. Throughout this time we have seen how devoted family members play a key role in supporting, enabling and empowering their loved ones.

Families desperately need peace of mind and deserve to feel confident about the future

Parents and family members provide support day-in and day-out, and year after year, often with limited opportunities to take a break. They also often become experts in their loved ones' care; co-ordinating support and advocating on their behalf.

We know that as carers of disabled adults become older, their caring role becomes harder. They may lack the energy they once had to deal with the day-to-day tasks and responsibilities, and once they begin to develop their own health issues and illnesses, may quickly lose the ability to provide high levels of care.

It is a common experience for the families we support to worry about 'what will happen to my loved one when I'm gone?' Our report shows that over two thirds of people caring for a disabled relative fear for the future. Despite this, few have felt able to put a plan in place – 75 per cent of families have not made a plan for what should happen when they are no longer able to provide care.

The following report explores families' fears for the future, the barriers to making long-term plans for housing, care and lifestyle, and outlines the changes needed to improve the situation. It is based on in-depth research carried out with disabled people and carers, and our experiences of providing support to families.

The challenges, recommendations and solutions highlighted in this report have national and local implications; from central government to local authorities, to commissioners and service providers. They cut across policy areas and sectors, focusing not only on provision of health and social care but also housing, welfare and other aspects of society.

This report does not simply aim to highlight the challenges faced by families with long-term caring responsibilities, but aims to form a constructive basis for change. Alongside the report, we are also publishing a toolkit 'Decisions to make: Steps to take' aimed at helping disabled people and their families to make decisions about future care and support.

Families desperately need peace of mind and deserve to feel confident about the future. We hope this campaign will be an important first step towards achieving this.

To find out more information, support our work in this area, and download the new toolkit, aimed at helping disabled people and their families make decisions about future care and support visit: **www.sense.org.uk/helpfamiliesplan**

Executive summary

Families of disabled people with complex communication needs often provide their loved ones with around-the-clock support. Family carers provide support day-in and day-out, and year after year, often with limited opportunities to take a break.

Although many disabled people with complex needs will live independently in residential services or in supported housing, many others remain living in the family home well into adulthood. As a result, family carers often continue to provide a high-level of support for their loved ones, as they themselves enter older age.

Due to the central role they play in providing care and support, many family carers have profound fears about what will happen when they are no longer able to fulfil their caring role. Despite this, only **25 per cent** of families have felt able to make concrete plans about who should care in the eventuality of their illness or death.

This situation is creating profound uncertainty and worry for the future among disabled people and their families. It also means that some disabled people with complex communication needs are at risk of suddenly being left in a situation of crisis, without suitable care having been put in place.

Methodology

The following report is based on 120 online survey responses, a representative poll of 990 carers, 40 in-depth interviews with families and disabled people, and a series of Freedom of Information (FOI) requests to local authorities in England. The research aimed to find out:

- How many older people are caring for disabled adults in the UK?
- How many family carers have made a plan for when they can no longer care?
- What are the main barriers to planning for the future?
- What is the impact of a lack of planning?
- What changes are needed to improve the situation?

Key findings

How many families are looking after disabled relatives in the home?

- We estimate that there are 1.7 million disabled adults being cared for by family or friends.
- There are currently 2 million carers in England and Wales who are aged 50-64 and 1.3 million carers aged 60 and over[i].

What is the level of concern?

- **81 per cent** of disabled adults said that they worried about how they would manage their day-to-day life without the support of family and friends.
- **67 per cent** of carers surveyed said they have profound fears about what will happen to their relative when they are no longer able to provide support.

How many have put plans in place for the future?

- **75 per cent** of family carers of disabled people have not made a plan for what should happen if they are no longer able to provide care.

What are the main barriers to planning?

- **77 per cent** of carers have found the process of making decisions about future care and support difficult, as the system is difficult to understand and navigate.
- Only a quarter of councils routinely support families to make contingency plans for future care options.
- One third of councils do not know how many disabled people who live in their area rely on friends and family for their care and support. This has an impact on how well councils support disabled people and their families to plan for the future, as well as impacting negatively on long-term planning of services.
- **40 per cent** of family carers believe that there are a lack of services available locally that can meet their loved ones' specialist needs, including in communication.
- **41 per cent** of family carers surveyed reported that navigating cuts to local services have increased the difficulty of planning for the future, and half of carers **(51 per cent)** have worries that future funding cuts will limit future options even further than at present.
- **95 per cent** of family carers said they had little or no trust in councils and local services to provide suitable care options for their disabled relative.

Recommendations:

The following changes would help to provide the peace of mind families need, and ensure that disabled people with complex needs have appropriate and timely arrangements for their future care in place:

1: Create a duty to ensure that plans have been put in place.
There should be a duty on local authorities to ensure disabled people aged 25 and over, have long-term contingency plans in place for their housing, care and lifestyle. 82 per cent of the carers we surveyed would support this.

2: Support families to make plans for the future.
Local authorities should provide specific and proactive support to disabled people and their families to develop long-term plans. Plans should be far-reaching and holistic, and include options for long-term advocacy and support.

3: Provide clear information about how the system works.
Local authorities, providers and voluntary sector organisations should do more to provide clear information on what services are available to support disabled people and their families in the short and long-term, and how to access them. This could include disseminating Sense's toolkit for families 'Decisions to make, steps to take.'

4: Ensure quality specialist services are available.
Local authorities and providers should work together to ensure that there are sufficient quality specialist services to meet local needs and provide choice for families. This should include staff with the right skills to provide support to people with complex communication needs.

5: Provide enough funding for local areas.
Central government should ensure that local authorities are adequately funded – not just to meet immediate care needs, but to enable the delivery of new and innovative models of care, such as supported housing. Such funding needs to be long-term and sustainable.

6. Provide more support to help families now.
Ensure that families are supported in their caring responsibilities while they are still able to provide support, by the provision of adequate support within the home, and access to short breaks.

Acknowledgments

Sense would like to thank all the individuals, families, professionals and stakeholders who have contributed to this work for being open and honest about their experiences, and sharing their hopes, fears and suggested solutions.

1 What will happen when I'm gone?

For 60 years, Sense has provided support to disabled people with complex communication needs, and their families. Throughout this time we have seen how devoted family members play a key role in supporting, enabling and empowering their loved ones.

Parents and carers of disabled people with complex communication needs often provide around-the-clock support, including help with personal and medical care, such as washing and dressing. They also provide practical support such as helping to organise appointments, support to manage finances, and facilitating access to social and employment opportunities[ii]. Carers provide support day-in and day-out, and year after year, often with limited opportunities to take a break.

Family members play a key role in supporting, enabling and empowering their loved ones

In addition to giving daily practical support, parents and other family members are often called upon to become the 'experts' in their loved one's care and communication needs. They play a central role in making sure that professionals understand their unique capabilities and securing the care and support services they need. Many families feel they have to work hard to co-ordinate the provision of care and support from the health and social care systems, advocating for their loved one in order to ensure the system meets their needs.

This was summed up by one parent who told us:

"Mostly the separate bits do their part but no one coordinates and pulls it together apart from the family. Mostly services are not interested in things that aren't directly to do with them. Occasionally signposting happens but it is never followed up to see if we were able to solve the issue."

Although some disabled people with complex communication needs will begin to live independently in residential services or in supported housing, many others remain living in the family home into adulthood – with family carers continuing to provide a high-level of support.

Fears for the future

As carers of disabled adults become older, their caring role becomes harder. They may lack the energy they once had to deal with the day-to-day tasks and responsibilities, and once they begin to develop their own health issues and illnesses, may quickly lose the ability to provide high levels of care. Some may also be providing support to other family members.

At Sense we know it is extremely common for the families we support to have profound fears about what will happen when they are no longer able to provide support for their loved one. Despite this, very few have made concrete plans about who should care in the eventuality of their illness or death. Older carers are being left to provide care with very little support, often until they reach the point of crisis.

Charles

Charles is 25 and was born profoundly disabled as a result of a rare syndrome. He lives at home with his parents who provide round the clock care for him. His father says:

"We are his consultant, doctors, nurses and everything combined through the experience we've picked up over the years."

The need to plan for the future is a pressing concern for Charles' parents. Currently all of his care is provided by his parents but this is becoming increasingly difficult. As they are getting older, they are finding that it takes them longer to meet Charles' care needs. Also, Charles' mother has worsening health and has congestive heart failure, breast cancer and a kidney stone.

"We know that the time is approaching where we will no longer be able to provide the care the Charles needs. We want Charles to be happy and well cared for, that's our ultimate priority"

The next step for the family would be for Charles to move to residential accommodation but this also concerns them. Charles has a unique, individual way of communicating and his parents know exactly what he needs at any given time – even though he can't express this through speech. His parents are deeply worried that staff in a residential facility wouldn't understand Charles' communication and be able to meet his needs. They have had years of having to champion Charles' needs with health and social care professionals:

"We want Charles to be happy and well cared for, that's our ultimate priority"

"It can be a fight. Doctors don't always listen even though we are the experts."

To further complicate the situation, Charles and his family live in a house provided the council. If Charles moves into residential accommodation, it is likely that his parents would lose their eligibility for a council house.

2 The scale of the issue

67 per cent of carers surveyed said they have fears about what will happen to their relative when they are no longer able to provide care

Fears for the future were a common experience among the carers and disabled people we spoke to – **67 per cent** of family carers we surveyed told us that they worried about how their loved one would manage their day-to-day life if they were no longer able to support them.

Disabled people themselves also told us that they lack confidence about how they will cope in the future – **81 per cent** said that they worried about how they would manage their day-to-day life without the support of family and friends.

Despite the level of worry and uncertainty for the future, the vast majority of carers and disabled people have not yet put plans in place for when family members are unable to care.

75 per cent of carers of disabled people have not made a plan for what should happen if they are no longer able to provide care. Of the families we spoke to, we found that older carers, aged 55+ were the least likely to have put a plan in place.

64 per cent of carers had not discussed options for long term care and support for their loved ones with their local council. This is despite the fact that half of carers expect that their local council will have to step in to provide long-term care and support.

Many feel unable to take this step. One parent told us: "I don't think about the future, as I find it frightening to do so."

Worry about long-term care for loved ones is an issue of national significance.

The caring population is ageing. There are currently 2 million carers in England and Wales who are aged 50-64 and 1.3 million carers aged 60 and over[iii].

This challenge is set to continue and increase into the future – There are currently 620,000 parents in the UK caring for disabled children and young people who are under the age of 20.[iv]

Only a quarter of councils routinely support family carers to make contingency plans for future care options

Sense estimates that there are 1.7 million disabled adults being cared for by family or friends. However, further research has found that one third of councils do not know how many disabled people live in their area who rely on friends and family for their care and support.

This has an impact on how well councils will be able to support disabled people and their families to plan for the future, as well as impacting on wider long term planning of services. Only a quarter of councils routinely support family carers to make contingency plans for future care options.

Local authorities are not under a legal duty to keep figures on the number of adults providing long-term care for disabled people, or to ensure that long term plans are put in place for each individual. Despite this, **82 per cent** of the carers we surveyed would support a new duty on councils to ensure there are long-term care plans in place for all disabled adults over the age of 25.

Despite the scale of the issue and the practical and emotional strain on disabled people and their families, Sense has found evidence of a lack of action at local authority level to address the issue. Of the local authorities surveyed, Sense found that **72 per cent** councils do not support disabled people to plan for the future.

Tim*

Tim is 55 and was born with severe brain damage; he has cerebral palsy as well as a long-term mental health condition. He is a wheelchair user and his mobility is very limited. Tim's complex needs mean that he requires around-the-clock care and support. He currently lives in a residential care home.

For Tim, attending church and going shopping are important things to him but the residential care home is rarely able to provide support to enable this to happen. This is leaving Tim feeling increasingly isolated and frustrated.

"All we want is to know that Tim is somewhere where his needs can be met, at the moment I have little hope of this"

Tim's mother, Sarah, is 76 and lives over 30 miles away from the home where Tim is a resident. Whilst Tim is now having his immediate care needs met in the residential home, Sarah still plays a strong part in his life and often finds herself needing to be an informal advocate for Tim and providing emotional support.

Sarah worries about Tim's future when she's no longer able to provide additional support:

"It is a great worry for us and would have a massive impact on Tim… he wouldn't have anyone to act as his advocate… We currently have to fight the care home at every turn to get what's best for him. All we want is to know that Tim is somewhere where his needs can be met, at the moment I have little hope of this."

* name changed

3 The impact of the issue

Emotional impact

A lack of long term planning and confidence about the future has a profound emotional impact on many disabled people and their families. Families told us:

"Worry keeps me awake at night. I am very concerned that my son and daughter are going to outlive my capacity to care for them. The thought of the future terrifies me."

"I am ageing; my son has out lived his expected life span. We live for each other and God only knows what would happen if I were to die before him."

"God only knows what would happen if I were to die before him"

One parent told us:
"We are not averse to taking responsibility. We are happy to give her as much as we can but there will be a limit of what we are able to provide and there will come a point where we no longer can."

A disabled man in his fifties said:
"My sister-in-law and my mum are my carers. They are 60 and 74 respectively and I'm worried what will happen when they have to give up or die."

Many of the people in this situation we spoke to admitted to feeling powerless, and sadly, many expressed the same wish:

"As all parents in this situation we hope they will go before us."

"He'd go before me would be the ideal situation, because I would at least have peace of mind… that I didn't have to worry about him."

"Sometimes I hope he dies before we do, which is an awful thing to think."

Concerns for the future aren't just limited to parent carers. We spoke to spouses and siblings who also raised concerns about how they would be able to provide support in the future:

"Mum is getting old. We have talked about siblings stepping in but if we can't then there is concern".

"I am already limited in what I can do. I keep wondering how life will be should I outlive my wife."

Reaching crisis point

Aside from the significant emotional impact, not having a plan in place for the future runs the risk of families falling into crisis when their ability to provide care is withdrawn; with short-term solutions needing to be found to continue ongoing support.

In this situation the local authority or the NHS will have to rapidly put additional care in place. They may also have to reassess the individual which will be time consuming as well as costly. It is difficult to quantify this as each individual's circumstances and needs will be very different.

Our research has found that one in five councils have no provision in place at all to support someone whose carer

is no longer able to care for them, and so will struggle to place individuals into suitable care.

People with complex disabilities often need to make the transition into a new environment slowly and carefully so they can gradually get used to the new setting and understand what is happening to them. If a sudden change becomes necessary, it can be challenging and frightening for the individual.

If a loved one dies without having made a plan for alternative care, there is also the risk that disabled adults with complex needs will be placed in crisis care placements which do not meet their specific needs or allow them to live the life they want.

49 per cent of the carers we surveyed believed that a change in carer would result in a deterioration of the health of their loved one.

Providing crisis care to a disabled person with complex communication needs can be significantly more expensive than a planned placement – particularly if this is caused by a carer suddenly being unable to meet someone's care needs. This places more pressure on service providers and already-strained local authority budgets.

The loss of a family member may also mean that the individual loses a valued advocate. Family members understand the individuals, how they communicate, who they are, what their preferences are and how to ensure that they have choice and control. Concerns for the future are therefore wider than how immediate care needs will be met, but also focus on how their loved one will be supported to have choice and control:

Parents told us:

"We spend a lot of time being advocates which is a full-time job on top of being a parent. When we are not around, I think, 'who the hell is going to do that to ensure her quality of life?'."

"We share the worries of all parents of disabled children that they will not access the same levels of support, understanding and advocacy once no longer living with us. Will they have access to appropriate and caring support services, access to their community and employment opportunities? Will they be happy?"

Noreen

"Noreen is delightful, with a mischievous sense of humour and so loving, but also, because of her disabilities, she requires full-time support", says 68-year-old Inge, who cares for her daughter, Noreen, at their home in London. The 35-year-old has learning disabilities, is quadriplegic, blind, epileptic and does not use speech to communicate.

Inge, who receives four hours respite care a week from the local authority, says she feels "under pressure, with little support." Her worry, as she gets older, is the "lack of quality services available locally if I am no longer able to provide care."

"I really worry about what will happen to Noreen if I can no longer take care of her"

"I don't think that the local authority has many options, and the decision would be based on 'where there's a bed available', rather than the appropriateness of the care."

Inge's worry and uncertainty about where to get reliable information, has prevented her from making proper provisions for the future. She has made adaptations to the house, like installing a downstairs shower with a hoist, for when the time comes that she can no longer take Noreen up the stairs. However, she knows she must go further.

"I really worry about what will happen to Noreen if I can no longer take care of her. If she's not happy where she is and with the people who look after her, she will refuse medication and food and drink. She becomes incredibly unhappy."

"I have been encouraged to think about the future, so maybe it's my fault that I don't have a plan in place, but I need more information and support."

4 Barriers to long-term planning

When speaking to disabled people and their families about the barriers to long-term planning and decision making, a number of themes emerged:

Lack of time and energy

In many cases, family carers are understandably focussed on providing day-to-day care and on shorter-term needs for support. This can mean that there is little time, energy and capacity to give considered thought to the longer-term future meaning that plans are not put in place, increasing the risk of reaching crisis point. One mother told us:

77 per cent of carers have found making decisions about future care and support difficult

"It's difficult to plan for the far future: always something in the way, the next set of assessments or transition."

Lack of support to understand and navigate the system

In addition to the practical barriers to starting the planning process, families told us that health and social care structures and processes are complex, and that it is difficult to work out where help can be accessed from. This can prevent them from seeking the support they need in both the short and long-term, as they may not know how to approach and navigate the system.

Our survey of carers found that **77 per cent of carers** have found the process of making decisions about future care and support difficult. Only **6 per cent** felt that the process was simple and straightforward.

We heard:

"It is hard to find help and I don't know who can help. Information is not easy to get."

"We are not given any information. I still cannot bring myself to do this alone."

"The Borough does not help with information on where to go or what is available in the area."

"We have always had to find out things for ourselves."

A lack of support from councils

The result of a Freedom of Information (FOI) requests to councils found that **72 per cent** of local authorities do not proactively support disabled people to plan for the future in the form of long-term and future care plans.

69 per cent of the carers surveyed said they do not feel that their council has done enough to support them with planning for the future. Several families we spoke to had struggled to get guidance and support from their local authority and had abandoned their efforts to start future planning as a result.

Families told us that they need practical and emotional support and encouragement from local authorities to help them to put plans in place – but this is often lacking.

"I would welcome early support to set up systems to maximise the chances of goals being achieved for and by her before we get to the point of being unable to perform the role of carers and advocates. Early planning is the key but it is proving difficult to make that start without knowing who and what can support the planning process."

"My daughter occasionally has an advocate – I need one too as it is a battlefield and there is no one there to hold you up."

"We are not given any information. I still cannot bring myself to do this alone"

Councils have a legal duty under the Care Act 2014 to offer people with 'care and support needs' information and advice about the available care options. Despite this, **51 per cent** of carers and people with support needs reported difficulties in getting information and advice from their council.[v]

Concerns around information and advice provision are also present within local authorities. According to recent research by Association for the Directors of Adult Social Services (ADASS), **21 per cent** of councils lack confidence that they will be able to meet their legal duty to provide information and advice to people who need social care.[vi]

James*

James and his wife care for their young daughter who has autism. She requires an "exceptional" amount of daily support, especially from her mum. This includes being constantly on hand to manage her anxiety which can escalate, and staying with her throughout the night as she does not sleep.

James feels that the lack of support from an early stage is why they are struggling as a family today. He recalls reaching out to Child and Adolescent Mental Health Services and being repeatedly told that his daughter's case was not "severe" enough.

Today he believes that "the system has given up on her". He has little faith that they will find services that will try to understand their daughter due to their past experiences. They don't think the right type of support exists for them – "or if it does, we haven't found it". This is a very stressful situation and they don't know who to turn to overcome it.

Due to their experiences, James and his wife do not trust the support services; they have had massive challenges. These battles have included going to an education tribunal because the local authority was refusing to carry out an assessment for their daughter's statement of education needs. This ended up being a two year battle because the local authority kept delaying things.

"The system has given up on her"

Whilst they have never been offered respite, James and his wife have also been reluctant to seek it. Although it might give them a few days break, they feel that the aftermath would not be worth it if their daughter had a bad experience and damaged their daughter's trust in her parents. The battles, lack of support, and experiences James and his wife have had has led to a consistent lack of trust of services – so they don't feel they can take the risk.

James and his wife have not felt able to plan for the future. They recognise that the current situation – where they completely support her themselves – is unsustainable but feel as though they have run out of options.

* Name changed

Promising practice: Worcestershire Council

Worcestershire County Council has identified the need to support families and carers who support someone with a learning disability to make long-term plans for the future. Working in partnership with local carers' forums and networks they have produced resources for families outlining options for the future and encouraging families to make plans.

Their leaflet, 'Planning for the Future' is available on the council website and further support is available from Worcestershire's Your Life Your Choice website. Through this information, Worcestershire County Council acknowledge that preparing for the future is a difficult subject that can lead to anxiety and worry but by providing the right information, advice and support can give reassurance.[1]

[1] Further information about housing options, legal and financial planning and the support available in Worcestershire can be gathered from the webpage (ylyc.worcestershire.gov.uk/care-and-support/carers/planning-for-the-future/).

Martin

Martin

Sense first met Martin after a referral from the local authority. Martin had been living in a nursing home and staff were concerned that he was becoming increasingly withdrawn and unwilling to interact with others. The home wasn't able to provide activities that Martin could participate in and there was a general lack of routine which left him feeling anxious and unsettled.

Following an initial assessment, it was agreed that Martin would be the happier in a supported living setting. Over a period of weeks, support workers spent time with Martin, getting to know him; his daily routine, communication needs, what's important to him and how best to support him. Staff built trust, familiarity and consistency and Martin was able to engage in the planning to move him to his new home.

Martin moved into his new home and was immediately involved in day-to-day activities: making drinks, helping to prepare meals and cleaning and washing up. He can choose different activities to do each day including arts and crafts and gardening.

"It feels like home!" he says.

Martin had not been outside for over 16 years due to his anxieties. Throughout his first year in his new home, staff gradually built up his trust and confidence to go outside. This started by opening windows and doors which Martin had always ensured were closed in the past. A few months after this staff members encouraged Martin to come into the garden – and after receiving support all that day Martin took his first steps onto the garden! This was a huge achievement for Martin which he is very proud of.

Promising practice: Supported housing models

Supported housing can offer greater levels of independence and choice for many individuals than traditional residential support.

In supported housing services, the people who live there are tenants in their own rights, with the responsibility and freedom that that entails. The property is not owned by the care provider, so the individual can freely change their provider, and design the support package that suits them best.

All supported living services should be tailored to the needs of the individual. There is no 'one size fits all' mentality; the service should be focussed entirely on developing and guaranteeing each tenant's independence.

Supported housing services can offer disabled people with complex needs improved outcomes, greater independence and can be much more cost-effective than residential care services in the short and long run.

Concerns about levels of funding in the system

Many families we consulted highlighted concerns about insufficient funding within the health, social care and housing sectors. **41 per cent** of carers surveyed reported that navigating cuts to local services have increased the difficulty of planning for the future, and half of carers (**51 per cent**) have worries that future funding cuts will limit future options even further than at present. Some families went further – with **47 per cent** stating a belief that their council prioritises cost-cutting over providing quality care.

"We will always be pushed to give more support to our son than we can and should"

Some believed that the lack of funding at a local level has created a disincentive for the local authority to provide timely support – with some only willing to offer provision in the short-term once crisis point has been reached – rather than providing timely help and support toplan for the longer term. One parent told us:

"The lack of resources means that I feel we will always be pushed to give more support to our son than we can and should."

"It is always a fight to get any service and everyone gets treated with suspicion."

Some families also considered that due to a lack of resources, they would be unlikely to get the support services which they should be entitled to, and which would be most likely to meet the needs of their loved one. One parent told us:

"It all seems great on paper; supported work settings, supported tenancy schemes, but there is no point without the resource to back it up."

Families were also concerned that the lack of resources had a negative impact on the quality of services available, leading to mistrust:

"Saving money is more important to them than quality or what we want."

"Unfortunately, the turning tide towards minimising expenditure means that people unable to strongly advocate for themselves will lose out. While I know these systems will provide support, I am not confident that this will be based on my daughter's needs rather than the need to minimise the level of expenditure."

"I don't trust them to find somewhere suitable, I'd have to be forceful as I worry they would simply look for the cheapest option. There is a trend for supported living at the moment and I don't feel that this would be suitable for my daughter unless there was a really good support team."

Concerns about the availability of funding for services, and the subsequent impact on service quality means that families are reluctant to seek short and long-term support, and are left to care alone as a result.

Mark

50-year-old Mark, from Peterborough, is a full-time carer for his 24-year-old daughter Kerrianne. They live at home, where she receives full-time support in all areas of her life, including with personal care and daily activities.

Kerrianne has epilepsy and learning disabilities. She loves trains, live music and trying on new clothes.

Ideally, Mark would like Kerrianne to live in supported living accommodation so that he can feel confident she has a home where she can be cared for long-term and thrive. However, his efforts to achieve this have been thwarted due to the poor quality of local adult social care services. When it seemed that a suitable arrangement had been found, the local provider was not able to make appropriate adaptations for his daughter's needs, and so the opportunity fell through.

The stress and worry of finding somewhere for his daughter led him to become a full-time carer, as this seemed like the only practical option available.

Mark says that getting support with care has been a constant battle. He feels that services do not prioritise his daughter's wellbeing and that family carers are often taken advantage of because councils are more concerned with saving money:

"We are emotionally blackmailed by social services; they know we won't walk away and we'll keep doing everything for free."

Whilst spending months appealing for more support at home, Mark's quality of life deteriorated to the point that he couldn't cope. Following this, the council finally offered his daughter 17.5 hours of support at home per week. However Mark believes the council only offered this as it was cheaper than residential care options.

"Saving money is more important to them than quality or what we want."

Mark is frustrated that there isn't a plan in place for when he can no longer care for Kerrianne, and this is great cause for concern:

"I've spent years trying to find a solution and I feel like I'm blocked at every turn by social services. I have no idea what would happen if I was sick. I expect that she would be affected by depression and more seizures likely. There is no one that knows her medication, how she can be manipulated, or gets scared in new situations."

"It's very stressful. I find myself hoping that she passes before me."

Lack of suitable services

24 per cent of the carers we surveyed, who had attempted to make long terms plans for the future, said they had been unable to find suitable options for their future that they would feel comfortable and happy with. For example, **31 per cent** felt that there was no appropriate housing provision locally.

95 per cent said they had little or no trust in councils and local services to provide suitable care options for their disabled relative

Disabled people with complex communication needs often require specialist services in order to meet their needs. Many families told us they were being offered more generic provision, or services intended for older people or people with mental health problems. These services are often not suitable, meaning that transition to them is not possible. Of all the carers surveyed **40 per cent** expressed doubt that there were services available locally that could meet their loved ones' specialist needs. Not having a viable alternative to the support that families are providing leads to a challenge or inability to make long-term plans. Families told us:

"When you have general services, they are not going to fit everyone. And it shouldn't be that these are the only things they can access. She might not want to. What she needs for a true quality of life doesn't feature highly… they are going towards people just existing; especially with things like strict time slots for people to provide care."

"We think our son could be supported in a very good care home. Our experience is that these do not seem to exist for people with complex multiple disabilities."

"He can't do anything without help since losing his sight 3 years ago. There is no rehab available because he is autistic – it's only available to elderly 'normal' people"

A fear that the services on offer would not meet their loved-ones' unique needs is a key reason that family carers continue to provide care themselves rather than seeking support from social care services. Many people we spoke to who already received a social care service said they worried that it was not sufficiently high-quality, and offered inadequate care.

Lack of local specialist services

Where specialist services do exist, they may not be in someone's local area. For some families, there are no services available in their local area that can meet their needs. This can mean that people are provided or offered services far from their friends or families.

Many people said that supported living would be suitable for themselves or their loved one but it simply wasn't available locally.

"For ten years we have tried to find suitable living accommodation for our son. He has always lived at home and we are constantly told our area 'does not do' residential it must be supported living."

For some families, this lack of local service provision means that they are being offered out of area services that are too far away for them to visit regularly. Whilst these services may be meeting the immediate needs of the person, removing them from significant relationships can have a detrimental effect on their wellbeing.

Distrust of local councils

Our survey of carers found high levels of distrust about local councils. **80 per cent** of carers told us that they have concerns about the ability of their local council to meet their loved ones' care and support needs in the future.
95 per cent said they had little or no trust in councils and local services to provide suitable care options for their disabled relative. Of the families we spoke to who already have a plan in place for future care and support, **40 per cent** are already seeking to avoid council involvement by relying instead of other family and friends assuming caring duties.

Parents told us that services also need to be sufficiently aspirational:

"I want it to be about her quality of life but unfortunately the way most services are going it's just about people existing – eat, sleep and a roof."

"Life for people with complex needs is much more than having their day-to-day care needs met, it's about being able to be independent, engaged and involved in communities and society."

Richard

Richard is 57 and is deafblind, with severe learning disabilities. He lives with his sister, Sharon, who has become his primary carer. Sharon supports him with personal care, liaising with social care, arranging medical appointments and leaving the house to visit the shops.

Richard hasn't always lived with Sharon. He used to live in a local independent living scheme but the placement broke down because of concerns about the quality of care. Sharon recalls:

"The quality of the care there was so poor, his health and wellbeing deteriorated dramatically. We had no choice but to take him out of there, he couldn't stay there anymore. It was then he moved in with me and my family – there were no other options"

"I will never trust the care system with Richard ever again and that is why I fear what will happen when I am gone"

Sharon now balances caring for Richard with a full-time job. Richard has a direct payment which the family use to employ a friend to be his personal assistant when Sharon is at work.

Sharon lives with high levels of worry and anxiety about Richard's future and what would happen if she wasn't there to fight his corner and make sure he can secure the support he needs:

"My biggest fear is him ending up in an institutional care setting and that there wouldn't be anyone to make sure he gets the support he needs.

"I would love for him to be able to move into a good independent living scheme but I'm not optimistic about this happening. Even If we could find somewhere, Richard has had such horrific experiences in the past that I can't see him agreeing to move out of the family home again.

I will never trust the care system with Richard ever again and that is why I fear what will happen when I am gone."

"Without support I would not be able to socialise or go out to do things I like."

"People tend to under-estimate my son and they may not be as ambitious for him as I am."

Families shared their aspirations for their loved one's lives with us:

"[My hope is] that she will be encouraged and supported to maximise her potential, be able to live in a supported environment and have social contacts, friends and peers, that those who support her and her peers will be able to communicate with her, that people supporting her will ensure that she is given the opportunity to participate fully in society and that she will be involved and expected to make choices with regard to all aspects of her life."

"I can't bear to think about him being isolated and unable to ask for help"

Fears about meeting communication needs

Disabled people with complex communication needs require personalised care, and need staff with expertise in communication to support them to receive and convey information.

If this is not in place individuals can't have choice and control over their day-to-day lives or express their wishes and feelings. Many families mentioned this concern and it had prevented several from placing their loved one in support outside of the family home. They told us:

"He is entitled to 42 hours [of support] but services available have no signers. What is offered to us is not very well planned. He can't communicate effectively. They only have basic training to supervise him. It is a big concern, even other people say it to me. If someone could sign he will feel at ease."

"When she gets assessments, they say 'well can't she go here?' Well, she could go there but there is no appropriate support when she gets there and no one to communicate with her…"

"A lot of respite services offered do not understand specialist communication methods. He is reliant on people because of this."

Learning how to understand and communicate with someone can take time, but many families said that staff turnover in services was so high that these relationships could not be developed or maintained. Even when effective relationships are established, these are often short lived as the staff member moves on.

Alex

23-year-old Alex, from Rotherham, has a rare genetic disorder that means that he can't speak, has sight loss and uses a wheelchair. He lives at home with his two siblings, and his mother, Tracey, and father, Gavin, who is Alex's full time carer.

Alex enjoys being outside, football and flashing lights. He has a great sense of humour and is a pleasure to be around, but his autism and OCD mean that he can become fixated on things, and because of his strength he can be obstructive at times.

Tracey and Gavin feel deeply let down by the lack of support they receive from the local authority and say that the pressure of caring has led them to experience mental health issues and even breakdowns.

Gavin says: "If institutions want us as carers in a domestic setting they need to provide the balance through respite. However, it's gradually being underfunded and our support structures are getting taken away. A significant amount of our respite has been cancelled, and the amount of overnight respite available per year has been reduced as the council is now providing fewer beds."

"We were supposed to have a new carer's assessment two years ago but it never happened. It's desperate. I am 54 and I didn't envision that I'd be changing my son's diapers now."

They are exploring the possibility of moving Alex into shared living accommodation, but say "the process is very complex and time consuming". Tracey says: "We approached social services to ask about having a social worker and told them what we required. It has so far taken 11 months and we have no definitive steps taken yet – its currently at the who is going to pay stage."

In the meantime, the parents have put Alex in their joint wills and decreed that his brothers will look out for his wellbeing, but say "it's not a role we want his brothers to fill – they have their own lives."

The couple recognise that the local authority is under huge financial pressure, and this knowledge only makes them worry more for the future and the quality of care that Alex may receive of the family are no longer capable of caring for him.

Tracey says: "It's deeply worrying. They will always go for the cheapest option and not what is most suitable. We have very grave concerns that they could pull funding at any time in the future and put his wellbeing into chaos."

This is a sector-wide issue; the annual turnover of direct care staff in the adult learning disability sector is 32 per cent, which means that, in theory, the entire workforce is replaced nearly every three years.[vii]

"Reorganisation and staff changing are so regular now you never speak to the same person, one writes the report and when you want to discuss it they have moved on and it's another 'professional' who does not even know the person in the report."

"Lots of places near us use agency staff with high turnover – this wouldn't work for my daughter; she needs to build rapport and have continuity, getting to know people is very important to her."

"Social workers are always changing now."

Expertise and understanding of needs

"It's a struggle trying to get social services to work with you. Instead they write up inaccurate reports, and think that they know it all."

The first step to getting support from social care services is to have an assessment to establish what the individual needs and how these needs should be met. Local authorities are legally required to carry out social care assessments of any adult who appears to have care and support needs.

We heard reports of people struggling to get assessments from care professionals who understood or had expertise in particular areas. This means that where the right services exist, and in the right area, families may struggle to find professionals who will understand the need to provide access in a particular setting.

Disabled people with complex needs often require specialist assessments due to the nature of their care and support needs, particularly around communication. Families told us that they often have assessments carried out by people who don't understand their loved ones' needs:

"It can be totally dependent on the member of staff or team you have at a particular council. I think most try their best but are impeded by a lack of true understanding about the condition or available services."

"It is pointless to have conversations about care unless they are with people who understand. I don't want people to think they just have to do everything for her. It's about getting her to do things for herself and encouraging her independence. It's faster for you to do everything for her – you need time and patience which people might not give her."

"We want others to see her as a whole person. Most of us don't want to just exist but for us to have choices."

Others highlighted that assessments were often focused on immediate care needs, rather than taking in account the wider abilities and aspirations of disabled people:

"It doesn't feel like we are asking for much. We want others to see her as a whole person. Most of us don't want to just exist but for us to have choices."

Having an assessment which doesn't truly take into account the needs or aspirations of the individual is a key barrier to receiving appropriate and meaningful services for the long-term. This also impacts on the abilities of families to plan for the future if they aren't able to access appropriate and suitable services for their loved one.

The assessment process was also reported as a point of concern for families with many fearing that reassessment would mean a reduction in services provided rather than an increase or scope to change things and plan for the future.

"I get nervous every year when it's her review that they're going to turn around and say she can't go to [the day service she attends] anymore."

Julia

Julia is a parent who cares for her young son who has complex needs. In 2013 Julia had an accident at work resulting in brain damage. Now Julia's husband is a carer for both her and their son.

Julia is concerned about safety in their house, including the physical condition of the house itself, and the lack of a stair lift. Julia says a number of social care assessments still have not been completed which has left them struggling. She says there have been occasions where people have come to carry out assessments but it has not been made clear exactly where they are from, what aspect they are assessing, or what conclusions were drawn. She feels there is also a lack of coordination between services themselves. As a result, Julia spends a lot of time chasing people and following up whilst the capacity for the family to do so decreases.

Julia says that her husband is increasingly struggling and has developed depression, "everything is on him and he hasn't even had a carer's assessment – there is no respite or plan". Julia is concerned that the impact of their situation will lead to family breakdown.

Julia feels the local authority have really let them down and it is part of a failing system that has made them dependent:

"We had a good life and then things changed. We are a young family and they will make us dependent. One example of this is that they still haven't put a stair lift in. I always fall and go to hospital. It shouldn't be that something detrimental has to happen for someone to do something.

"We need support as an entire family"

Why have they not provided us with help? We are not being checked on. If something was to happen, whose fault would it be? I went through the complaints procedure and no response. No one person is ever responsible.

When you do everything you are supposed to do and this happens – why would you trust? When the crisis of social care is spoken about it is always in relation to the elderly not young families like us. These are basic human rights".

Julia says they always worry about the future for their son if they were no longer here. She says: "we need support as an entire family".

Availability of advocacy services

Family members provide a significant role in supporting people to have choice and control over their lives and communicating this with decision makers. Planning for the future is therefore more than simply considering what kind of support, who will provide it and where but who will support the person to make choices about their life.

To enable someone to understand and make choices, any advocate needs to understand the individual and their communication needs

Councils have a legal duty to provide an independent advocacy service under the Care Act 2014, however there is evidence to suggest that councils are not always fulfilling this duty. A survey undertaken by the Advocacy Action Alliance found that expenditure on advocacy services under the Care Act was much lower than it should be. On average spending was **50 per cent less** than it was expected to be.[viii]

For some people with more complex needs, having advocacy provided on a case-by-case basis is not an effective solution. To enable someone to understand and make choices, any advocate needs to understand the individual and their communication needs; this is rarely something that can be achieved in the short-term and requires someone to truly know the individual. Alongside this is the priority for the person to know and trust the people who are supporting them to make decisions.

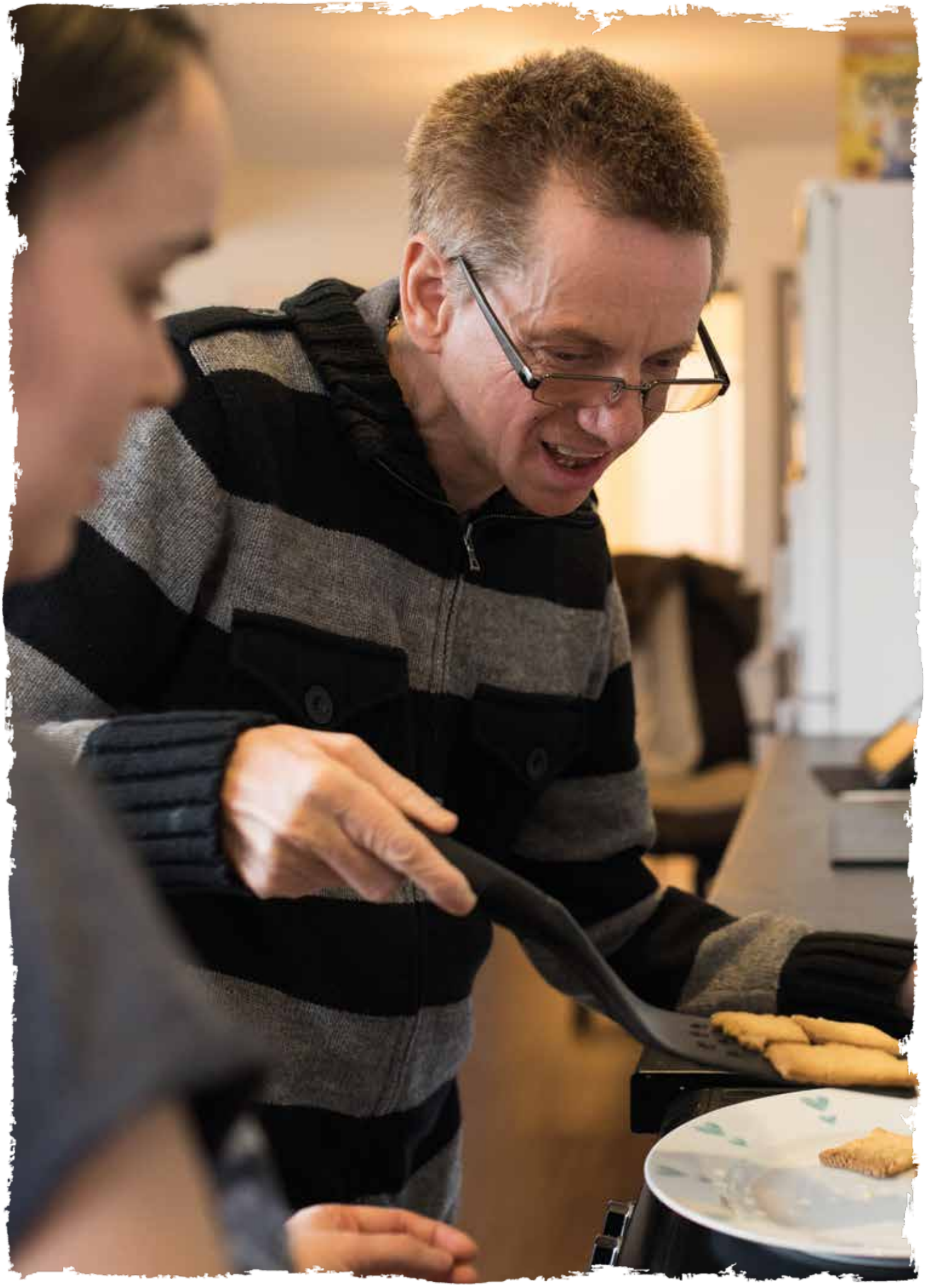
The Advocacy Action Alliance found that two third of providers across seventy-two councils had commissioned advocacy services for less than one year. This suggests that some councils have been unable to plan advocacy services into the long-term, which foster uncertainty and anxiety amongst some disabled people with complex needs and their loved ones.

Promising practice: long-term advocacy and circles of support

For individuals who require long-term advocacy the 'Circle of Support' model can be very helpful.

Circles of Support is an advocacy model where a group provide advocacy and support as a community for the individual who needs it, rather than the advocate being a single person. The group is chosen by the individual and, where possible, includes people with a variety of skills and knowledge but all focused on the best interests of the person in question. The people in the circle can change and develop over time depending on the wishes and needs of the individual and their capacity to provide support. The role of the circle is to empower the individual at the heart of it and support and enable them to make decisions about their life.

The benefits of a Circle of Support model is that individuals can draw on a wide range of skills and knowledge rather than depending on one single person to provide this.



5 Conclusion

Family carers play a very significant role in our society. Using ONS data we estimate that carers deliver 130 million hours of care per week, which we value at £2.2 billion. This is equivalent to £318 million per day or £115 billion per year. This data demonstrates the amount of support that families provide and the risk to the sector, should they no longer be able to do this.

Disabled people with complex communication needs and their families deserve to feel confident that they will always be well-supported. The findings of this report show that there are significant and genuine fears that this will not be the case.

This is a complex issue and as such there is not a simple solution. There are, however, steps that can be taken and opportunities to develop new ways of working which put disabled people and their families back in control of their own lives and able to plan for the future.

For disabled people with complex needs, solutions may come from a number of sources and be delivered by a range of services, from day services to supported housing models. Different service types will meet the needs of different people and a range of services need to be in place to allow people to make an informed choice.

The social care system needs to be adequately funded so that commissioners can continue to develop and offer innovative ways of providing care and support. Commissioners and providers need to be able to work together to ensure that quality, personalised services are available to meet needs.

Planning for the future, or changing how people are supported, isn't something that can be achieved instantly or overnight; it takes time. Transition to new services and building trust that they can meet needs and aspirations is a process, and disabled people and their families need to be supported and enabled to do this in a timely way. Families should not be left in situations of crisis or forced into short-term decisions that compromise their care and support.

6 Recommendations

The following changes would help to provide the peace of mind families need, and ensure that disabled people with complex needs have appropriate and timely arrangements for their future care in place:

1: Create a duty to ensure that plans have been put in place.

There should be a duty on local authorities to ensure that disabled people aged 25 and over, have long-term contingency plans in place for their housing, care and lifestyle. 82 per cent of the carers we surveyed would support this.

2: Support families to make plans for the future.

Local authorities should provide specific and proactive support to disabled people and their families to develop long-term plans. Plans should be far-reaching and holistic, and include options for long-term advocacy and support.

3: Provide clear information about how the system works.

Local authorities, providers and voluntary sector organisations should do more to provide clear information on what services are available to support disabled people and their families in the short and long-term, and how to access them. This could include disseminating Sense's toolkit for families 'Decisions to make, steps to take.'

4: Ensure quality specialist services are available.

Local authorities and providers should work together to ensure that there are sufficient quality specialist services to meet local needs and provide choice for families. This should include staff with the right skills to provide support to people with complex communication needs.

5: Provide enough funding for local areas.

Central government should ensure that local authorities are adequately funded - not just to meet immediate care needs, but to enable the delivery of new and innovative models of care, such as supported housing. Such funding needs to be long-term and sustainable.

6. Provide more support to help families now.

Ensure that families are supported in their caring responsibilities while they are still able to provide support, by the provision of adequate support within the home, and access to short breaks.

References

[i] Office for National Statistics, Census Data 2011

[ii] Yougov poll of carers, commissioned by Sense, sample week beginning 5th December 2017.
81 % provide personal care/hygiene support.
92 % support with meal preparation.
95 % support people to attend medical appointments.
83 % provide support with managing benefits and finances.
51 % support with finding employment and volunteering opportunities.
93 % provide support to enable access to social activities and hobbies.
56 % have provided support to find suitable accommodation.

[iii] Office for National Statistics, Census Data 2011

[iv] Contact, Caring More Than Most; A profile of UK families caring for disabled children. https://contact.org.uk/media/1169000/caring_more_than_most_full_report.pdf

[v] TLAP, Care Act 2014 Survey https://www.thinklocalactpersonal.org.uk/Latest/TLAP-Care-Act-2014-Survey-Results-and-Easy-Read-/

[vi] ADASS, Budget Survey 2017 https://www.adass.org.uk/adass-budget-survey-2017

[vii] Skills for Care, NMDS-SC, Dashboards

[viii] Mewbigging, Ridley, Sadd, University of Birmingham, Commissioning Care Act Advocacy: A Work In Progress January 2017

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connecting sight, sound and life

About Sense

Sense is a national disability charity that supports people with complex communication needs to be understood, connected and valued. We are here for every person who faces communication barriers in a world that relies on being able to see and hear well to be connected. Our flexible and personalised services empower people to communicate and express themselves – be it through speech or sign, touch or movement, gesture or sound, art or dance. Together, we connect differently and campaign passionately for the right to lead connected and fulfilled lives.

If you, or someone you know, require this information in a different format, please contact Sense Information and Advice – contact details below.

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