

“
**Who will care
after I'm gone?**
”

AN INSIGHT
INTO THE PRESSURES
FACING PARENTS OF PEOPLE
WITH LEARNING DISABILITIES

FitzRoy
transforming lives

WHY THIS REPORT IS IMPORTANT

BY **ANNA GALLIFORD**
CHIEF EXECUTIVE OF FITZROY

As a charity working day-in and day-out with people with learning disabilities, we are acutely aware of the pressures and challenges that they, their families, and the care professionals who support them routinely face.

While researching our last report, A Plan for Life, a number of parents we spoke to were so profoundly worried about what would happen to their son or daughter when they were no longer around to look after them, that they sometimes hoped their children would die before them. Shocked, I asked others within FitzRoy if they had heard that sentiment before and was told it wasn't unusual.

That's why we have undertaken this research with parents and the care professionals who support people with learning disabilities, to better understand the level of worry and anxiety that can lead parents to such a desperate point of view. We held a series of focus groups to hear from parents first-hand, as well as conducting a survey with care professionals to get their perspective. We also held in-depth interviews with parents to capture their personal stories more fully.

The findings we have drawn out from that research paint a depressing picture for the current system of support for people with learning disabilities, writ large in the desperation of the people who are closest to them. It is clear that a great deal of anxiety about the future comes from the difficult reality of the present.

The ongoing cuts to budgets and services are having a profound, detrimental effect on the individuals living with a learning disability and the people who support and care for them. Parents are exhausting themselves because they

feel they have to fight for every scrap of support for their children, while care professionals feel frustrated that they cannot do more.

The industry as a whole is struggling with staff retention and our research points towards some of the reasons behind this, including the perceived social status of care workers. This should be addressed head on and is coming to the fore with the increased Living Wage, which we welcome.

There is no magic answer to this, and there will certainly be no massive injection of funds to make things better. Times are extremely tough in social care and all of those involved in the sector need to work smarter, more collaboratively and openly, and consider radical ideas to improve the care and support they provide.

In this report, we outline the practical steps we believe would start to address some of the issues brought sharply into focus in this research. We will do everything in our power to help make those steps a reality. My hope is we can reach a point where no parent feels such despair and the same bleak conclusion as the ones that inspired this report.

Thank you,



Anna Galliford
Chief Executive



In this report

Introduction from Anna Galliford, Chief Executive of FitzRoy	Page 1
The current landscape	Page 2
Key findings – at a glance	Page 3
What they told us	Page 4 - 19
Research methodology	Page 20
Conclusion and recommendations	Page 21 - 23
About Fitzroy	Page 25

THE CURRENT LANDSCAPE

A learning disability affects the way a person understands information and how they communicate. People with learning disabilities usually need support in life with everyday activities such as managing money, household tasks and socialising, and may take longer to learn, due to a reduced intellectual ability.

People with learning disabilities represent a broad spectrum of levels of ability; some people with learning disabilities are able to do much themselves, while others live with severe associated physical

disabilities, in some cases unable to speak for themselves, and requiring round-the-clock care. Learning disability shouldn't be confused with mental health issues or dyslexia.



Prevalence

- Approximately 1.5 million people in the UK have a learning disability. Over 1 million adults aged over 20, and over 410,000 children aged up to 19 years old have a learning disability. [1]

- An estimated 350,000 have profound learning disabilities. [2]

- It is estimated that by 2020 the total amount of people needing learning disability services will outstrip those needing mental health, substance misuse, and physical disability services (this excludes people over 65). [3]

What happens when I die?

- 29,000 adults with a learning disability live with parents aged 70 or over, many of whom are too old or frail to continue in their caring role. In only 1 in 4 of these cases have local authorities planned alternative housing. [4]

- By 2030 the number of adults aged 70+ using social care services for people with learning disabilities will more than double. [5]

Scale of cuts

- Taking into account population growth, between 2009-10 and 2014-15 net spending per person by local authorities was cut by 23.4%. [6]

[1] Learning Disability Observatory, 2011, The Estimated Prevalence of Visual Impairment among People with Learning Disabilities in the UK in the UK report, (online), available at: <https://www.rnib.org.uk/sites/default/files/Emerson%20report.pdf> (Accessed 28 October 2014)

[2] NHS Choices

[3] Cordis Bright, Tom Noon Presentation

[4] <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/>

[5] Report - Estimating Future Need for Social Care among Adults with Learning Disabilities in England

[6] (IFS) from Tom Noon presentation

KEY FINDINGS AT A GLANCE

Parents told us their main pressure points

WHO WILL CARE AFTER I'M GONE?

The biggest concern facing parents of people with learning disabilities is the question of what happens to their son or daughter after they die. They need reassurance that practical and emotional support will be available to their children when they are not around to make it happen.

PAGES 4 - 7

A CONSTANT FIGHT TO BE HEARD

This concern is driven by the difficult reality of the present and the amount of energy, patience and commitment they need to secure decent care and support for their sons and daughters. They told us they have to be 'in crisis' to be heard.

PAGES 8 - 11

CUTS IN FUNDING AND LACK OF CONTINUITY OF CARE

Many of the parents we spoke to told us they were fearful of the impact of spending cuts on the provision of care available. They also said they want to see care work given the priority it deserves as both a career and a public service, to stop the high turnover of staff which results in a lack of continuity of care.

PAGES 12 - 15

THE WRONG ASSESSMENT

The parents we spoke to told us they have very little confidence in Social Services giving a correct assessment of need, with many reporting the dreadful consequences that can result from incorrect assessments.

PAGES 16 - 19

WE ASKED OUR FRONT LINE CARE STAFF* ABOUT THEIR CONCERNS

Many told us that they love their job and they wouldn't want to change career, however there are frustrations. More than a third of those we spoke to said that their biggest concern is the spending cuts and how they will affect their role and the support they give. Eighty per cent who responded to our survey report that their job would be more appealing if it had a higher social status.

*Throughout this report we refer to front line care staff as care professionals.

“
What happens
to my daughter
when I die?
Whose responsibility is
it to care for her?
”

WHO WILL CARE AFTER I'M GONE?

“You can write all the bits of paper that you like but, if it is not enforced, then it is worth nothing.”

Our research shows that families are deeply concerned about the long-term future for their sons and daughters, including the question of responsibility for their welfare after the main family carers have died.

One in three parents say that they fear for the future of their children after they are gone. After a lifetime of struggle to secure appropriate care for their loved ones, and a constant vigil to protect them from abuse and neglect, they have lost trust in the system to provide adequate safeguards when they are no longer there to oversee the process. One parent says: **“It is like a ship heading for an iceberg and nothing happening to change its course.”**

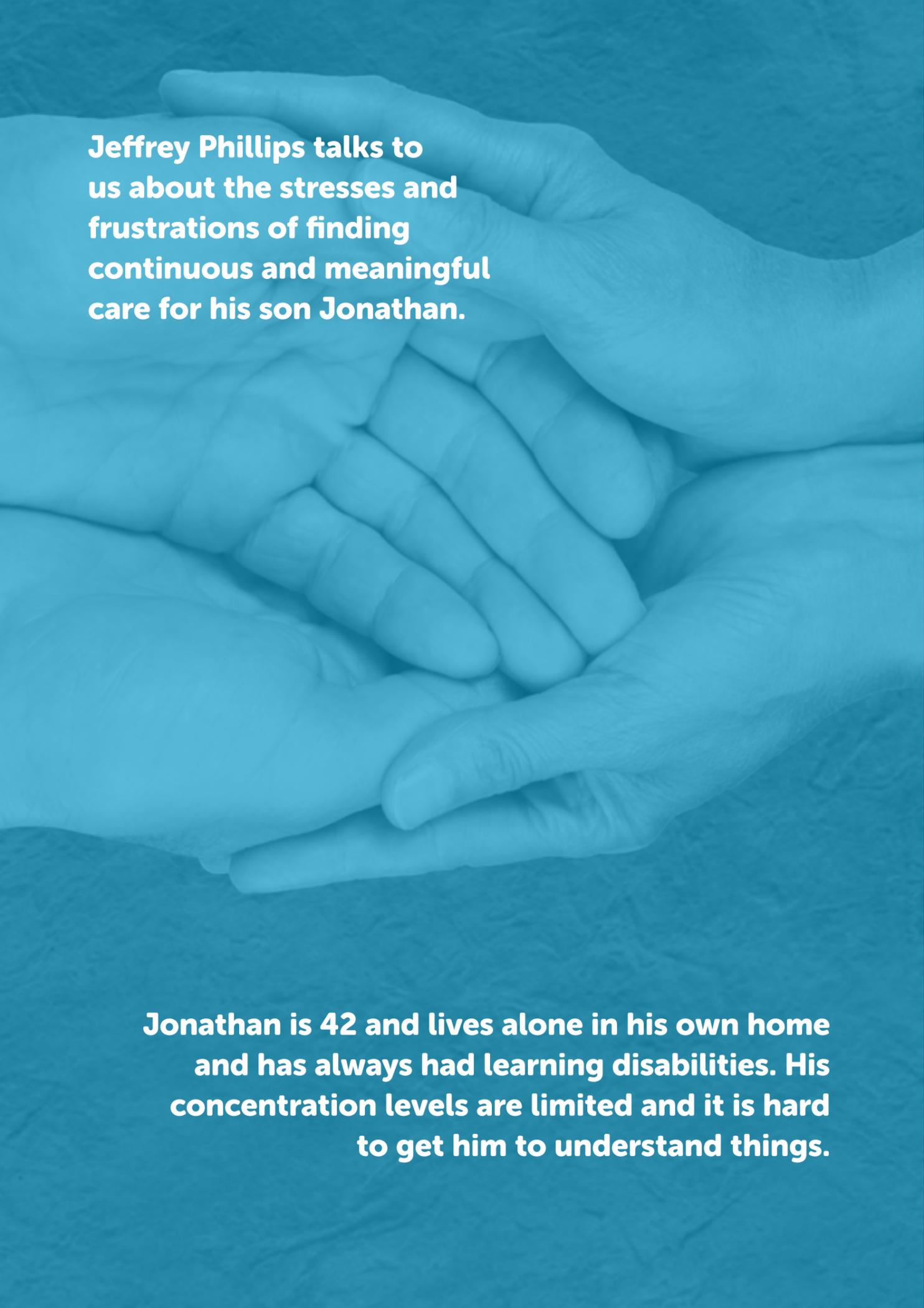
Parents told us that they have given a great deal of thought to arrangements for their children's care in the event of their death, and have sought legal advice to prepare for the future. However, their sense of helplessness is compounded by the limitations to legal arrangements as the law stands.

A Will establishes how much money will be left to a son or daughter, but gives little assurance about how it will be used to cover the cost

of care. Few parents know of the mechanism of setting up a discretionary trust which will both follow their specific wishes for future care arrangements and also protect the interests of their son or daughter. Appropriate and very specific legal advice is essential for each family circumstance.

Parents are extremely reluctant to pass the burden of care on to other children, or to members of their extended family. Although they would encourage other family members to maintain the relationship, they feel that it is unfair to expect them to assume the role left by parents. This is particularly the case when siblings have their own families to care for.

- One in three parents report that their child outliving them and not being able to care for themselves, or oversee their professional care, are their biggest concerns.
- Nearly three quarters (67%) of parents of sons or daughters with learning disabilities would be in favour of an 'adult adoption' system.



Jeffrey Phillips talks to us about the stresses and frustrations of finding continuous and meaningful care for his son Jonathan.

Jonathan is 42 and lives alone in his own home and has always had learning disabilities. His concentration levels are limited and it is hard to get him to understand things.

CASE STUDY

"What happens when I'm not there to keep the plates spinning?"

“

My late wife was his main carer while I was in business. When she died in 2004, I took over. Jonathan is lucky to have his own home, and we've always tried to help him lead as independent a life as possible, never wanting him to live in an institution.

In 2006 he was the victim of scammers who cleared out his bank account, and I realised I needed outside help. I called Social Services and they stepped in with twelve hours a week support. The first person that came in was very experienced and a brilliant carer. She understood that his mental wellbeing is as important as his physical state. Not only did she help him with cleaning and practical things, she made sure he always had something to look forward to. Jonathan was very happy. Unfortunately she had a personal tragedy and she had to leave. Since then things have become inconsistent and less productive.

We've had many different support staff coming in and the good ones seem to end up either being promoted or moving on. Jonathan has had eight staff in four months. With each person that comes in we have to start all over again, explaining what he needs. Continuity is everything, you can't set and achieve acceptable standards without continuous care, but there is a wider problem within this industry.

Care workers have a really important job and we are asking them to often work unsociable hours, be well-qualified and trained, be able to drive and own a car, be sensitive and caring, and all for just over £7 an hour.

A while ago my daughter and I were in a serious car accident. Luckily we both survived but it brought home to us how dependent Jonathan is on us for a decent quality of life. If we hadn't survived he'd have been in a terrible state.

We are the 'electricity' that keeps the plates spinning in the air. We have to be vigilant all the time, we have to complain to Social Services. He'd never complain on his own behalf. Without us he would be totally reliant on Social Services providing the right care, and our experiences to date don't fill me with confidence.

If I could have anything for Jonathan it would be the certainty that he would always be well cared for after I've gone, and that his mental wellbeing is given as much priority as his physical wellbeing. I want to know that if something happened to me and my daughter, there would be somebody there who knows Jonathan; has been his carer for some time; and could help him cope with everyday problems which would arise without the aid of his immediate family.

By Jeffrey Phillips

”

“
The parents who
shout
and cause problems
are the ones that get
results.
”

A CONSTANT FIGHT TO BE HEARD

“I wrote to MPs and everything. It isn’t until you go into it that you realise that you have to shout from the rooftops or nothing will happen. You have to be really threatening or nothing happens. It’s horrible to have to threaten.”

When we delved further into the reasons why parents were so concerned about a future for their children when they were no longer around, it was clear that it was driven by the sheer constant struggle of the present. Parents told us of their problems trying to obtain appropriate care for their loved ones and the need to remain vigilant at all times against the risk of exploitation or abuse. They say they are deeply concerned about what will happen when they are no longer able to act as advocates for their children, with abuse and neglect stories in the media, such as Winterbourne View, a constant and harrowing reminder of the risk to vulnerable people.

Parents feel they have to change their behaviour to become pushy and even aggressive in the face of indifference, in order to demand the support and care to which their children are entitled. They say they don’t get anywhere unless they fight. This leaves children whose parents are unable to challenge the authorities at a significant disadvantage.

This works both ways, with many front line care professionals showing a strong desire for parents and families of people with learning disabilities to have confidence in their ability to provide appropriate care. They would like parents and relatives to work more closely with them to help them do their jobs. So often a confusing and unclear system seems to be at fault, creating a gulf between the needs of the parents and the work of the care professional.

■ **96% of care professionals would like parents and families of the people with learning disabilities they care for to have more confidence that they are providing quality care.**

■ **88% of care professionals would like parents and families of the people with learning disabilities they care for to work more collaboratively with them.**

“We need to push for funding and places and make a nuisance of ourselves. I’ve dealt with people where I see their eyes glaze over and think ‘here she goes again’, well I am, because I’m trying to help my loved one.”

Bill and Heather Fleeman's son James was born with a rare chromosome disorder resulting in some physical and learning disabilities.

He was nearly two years old before taking his first steps, and could only manage two-word sentences until he was five. But James always had a very positive outlook on life, and despite his limited verbal communication, Bill and Heather referred to James as their "little communicator" due to his great facility to relate to people.

CASE STUDY

"Two years of struggle, uncertainty, and often despair."

“

Our major nightmare was finding the right school for James. Problems started when we had to choose a suitable secondary school. With reservations, we eventually accepted the advice of the educational experts at the Local Education Authority (LEA) to send James to the local school. This was a huge mistake, James was severely bullied. Despite the school's best efforts he would return home with his hair matted and his blazer wet with other boys' spit. More serious episodes of bullying also occurred which the school seemed helpless to prevent. The head teacher admitted that James was unsuited to the school and suggested we ask the LEA to find more appropriate educational provision for him. We felt that James needed the structured and protective environment provided by a specialist residential school.

The LEA were initially sympathetic but we were about to embark on an emotional rollercoaster which would become the most stressful two years of our lives. The LEA were slow to get things moving, but as they seemed to be going in the right direction we were not unduly worried, except that James was still having to put up with an intolerable experience at his current school. Eventually the LEA's educational psychologist produced a report that recommended that James attend residential school. We were so relieved.

Then it started to unravel. After a series of vague letters we received one which implied that, after all, the best educational provision for James was his current school! The educational psychologist produced a new report, which was almost identical but removing the conclusion that James needed a residential placement. We sought legal advice but were astounded to find that an appeal to the Educational Tribunal was not possible as the LEA's review into James' educational provision had never been formally concluded. Eighteen months had passed and we were back to square one.

We were getting desperate and James was now refusing to attend school. Only after some persistence by us did we receive a visit from the educational welfare officer who arranged four hours a week of home tuition.

We wrote a letter of formal complaint to the Chief Executive of the Council but were devastated to get a letter advising that their initial findings indicated no wrongdoing by the LEA, just misunderstanding on our part, and that they would respond more fully in due course. We did not know where to turn and were at breaking point. And then suddenly one morning the P.A. to the Chief Executive called us and advised us that the Council had changed their minds and were willing to place James in a school of our choice, within reason.

We never discovered the reason for this change of mind, and although it was all over we were physically and emotionally exhausted. After two years of struggle, uncertainty, and despair, James started at his new school where he spent five very happy, constructive years. He managed to put his awful experience behind him and recover his self-respect and confidence.

James, now 33 and happily sharing a house with other vulnerable adults, is a sociable and courageous young man and has been heavily involved in a campaign against bullying and hate crime which included giving a presentation to the Metropolitan Police. One day a week he is employed by 'Advocacy For All' where he advises other vulnerable young people in dealing with difficulties in their lives, including bullying. Amazingly, his place of work is the very school in which he himself was bullied.

We are very proud of James and all he has achieved.

By Bill and Heather Fleeman

”

“
It reached crisis point when my Dad died and my Mum was seriously ill, they finally came back and said they would give us funding for my sister – but only for six months.

There is no longevity, what happens afterwards?

”

CUTS IN FUNDING

Our research reveals that spending cuts are having a profound impact on the quality of care available to people with a learning disability.

More than half of parents who took part cite spending cuts among their most urgent concerns and said they were fearful about the future; many were able to give examples of services that had significantly helped the wellbeing of their son or daughter, which were no longer available. Their concerns were echoed by care professionals with one in three worrying about their role in providing support as funding is reduced or withdrawn.

Continuity of care is also a big issue for parents.

Difficulties in the recruitment and retention of staff, exacerbated by the cutbacks in social care funding and by low pay, jeopardise the relationship with carers. Constant changes in personnel make it difficult for a carer to really get to know the person they support and their family, and to understand what works best for them.

Two-thirds (67%) of parents report that increasing the value and status of people working in care roles would make the most difference to their lives and alleviate their concerns.

Funding constraints appear to be straining the relationship between carers and families. Nine out of ten care professionals said that they wanted families to understand that they were providing quality care, while the same number wanted parents to do more to help them understand the person they cared for.

Parents acknowledged that low pay is detrimental to the quality of care and affected continuity. One parent says: “If quality people were paid a decent wage, then money would be saved in the long run because recruitment and agency fees would be avoided. If the wages were increased you would get a higher quality of staff.”

“I discovered I could earn much more as an office cleaner than a carer, and have so much less responsibility. A carer is lucky to see £6.70 an hour or £8.50 an hour with advanced training. But the responsibility they have, and the criticism they face if they make a mistake, are intense.”

Peter and Mary Connor have cared for their son Tom for the past 35 years.

Tom has a range of learning disabilities, he can't communicate with words, can use a few Makaton signs, and is physically weak, often needing a wheelchair. Tom gets his parents' attention by pointing at things. He can shake his head, but conversation is very limited. He can't walk outside on his own, so they take him in a wheelchair. Every day he goes to places he can meet other people with learning disabilities, such as day services, and he gets a huge amount out of this.

CASE STUDY

"The system is a maze."

“

We are looking at the future, but often we are overwhelmed by worries. Funding cuts have led to issues around transport for Tom. For donkey's years they would send the same car and driver and they got to know him. They were very experienced, and always the same. Now they can't afford to send their own transport so a taxi picks him up and the driver can be different each time. We worry about something going wrong on the journey.

Tom can't speak to say who he is and where he needs to go. We worry about where he could end up. It is the worry each time he gets in a taxi, if something goes wrong, will the driver know what to do?

Another big issue facing us is around Tom leaving home. We know it has to happen because we are getting older and any young lad of 35 should be living with his own age group, not with Mum and Dad. **We're both finding it extremely difficult, we feel guilty, and upset, and it is terribly frightening.**

The process started well, Tom had an assessment from a lovely person from Social Services. They then sent us details of a great place which would have suited him, but we were told he couldn't go there even though it had vacancies. It has been a year now and we have only been shown two other places, both of which were totally unsuitable. Sometimes it feels easier to ignore the problem and keep Tom at home, but we know that we can't do this forever.

The more people I talk to the more I realise that until you're desperate nothing much will happen. It feels like they won't house him until we're ready to drop. We have to do all the chasing, and each time we feel frustrated as we don't get the information we need. The system is a maze. Other people who have been through the same thing tell us we need to lie and say we are 'in crisis', or we need to lower our standards and put him in the next place that comes along. But we can't do either of those things, so we are now forced to become those annoying people who phone up every day and make a nuisance of themselves, just to get heard.

It is the mental stress of reaching this stage and having to deal with it. It seems there is no easy way unless you're a millionaire. At least when you are looking at putting an elderly relative into care, they can usually voice their worries, but Tom can't voice his.

We wish Social Services would understand how difficult it is to even pick the phone up to call/chase them. The guilt and upset it causes means that it is easier to put the whole business 'on hold'. So, we get nowhere! It's a nightmare. **If there was one thing we'd change it would be more contact, help, and information from Social Services.** We want them to give us information, explain the system, hold our hand, and tell us how long things will take. In a year we've had around two phone calls and we've done all the rest. The whole process feels lonely and we worry time is running out.

By Peter and Mary Connor

”

“
An inaccurate
assessment is
life or death.
They are usually
incorrect.”

THE WRONG ASSESSMENT

“Why on earth would anyone think parents would want to send a child hundreds of miles away? It punishes parents and their children. It isn't about just plonking them somewhere to tick the box and get rid of the problem.”

The seeds of concern about what happens to their children when they are no longer around are often sown in parents when they first encounter the care system.

Our research highlights that parents worry about incorrect assessments of their son or daughter's needs, which has a profound impact on provision of care. Once an assessment has been made it can be extremely difficult to overturn, resulting in an inappropriate care pathway for many years.

Parents complain that social workers make incorrect assessments because they fail to engage in meaningful consultation with people with a learning disability, preferring to consult parents.

The situation is becoming more complex because many local authorities are changing care thresholds, i.e., the criteria you have to meet to be classed as eligible for services, as a way of rationing care because of funding constraints.

Parents feel let down by the lack of consultation from local authorities and poor communication, which leads to decisions that are not in the best interests of their son or daughter.

They also complain about the lack of advice available to parents of children with a learning disability to help navigate their way around the health and social care system.

“He is very capable, but professionals talk to me instead of talking to Tony. He is often ignored. He has lived 52 years, he has had plenty of experiences, please listen to him, not just me.”

Marian Crawford's daughter Clare has Down's Syndrome, is 27, and very able. She travels independently, catches the bus to her job working for an internet company that sells window blinds, and is a trainee at a community café. A member of a Mencap drama group, she loves being out and socialising with people her own age.



Both Clare and her family felt it was time for her to move out of the family home, so Marian contacted Social Services and asked about Supported Living. This would be a way for Clare to live independently in a house managed by a housing provider, with support by a care provider.

CASE STUDY

"An incredibly traumatic time."

“

We were told it could take two to three years but we were prepared for that. However, within a month a placement was available! Clare met up with two other young women, a four bedroom house was purchased by a housing association (three tenants and a sleep-in staff member), and FitzRoy became the chosen care provider. I cannot fault the way the house was set up and the preparatory work done with Clare to help make the transition as stress-free as possible.

Unfortunately things soon unravelled. One young lady left after ten days and another had extreme behaviour – she became violent and ended up leaving the house. We hadn't been warned of the chance of violent behaviour before Clare had moved in, and neither had the care provider, and the result has been awful.

Clare had to see a psychologist because she had been so scared. She used her computer as a comfort blanket and was waking up and using it in the night when she had frightening memories. With hindsight we realised the assessment of need had completely failed.

Clare ended up living on her own for nearly a year which was the last thing she wanted. Some of the staff left, and there was little security.

The other two bedrooms remained empty. We would have liked some of Clare's friends to move in who were getting ready to leave home, but you have no input into the system. It seems to work on priorities and we feel that Clare got her place so quickly, because she was part of the package for a priority placement. This seemed like madness as the rooms remained empty instead.

After eight months a lady was brought in. She is in her late forties and has Down's Syndrome, but the age gap means they have very different interests and needs. They don't do much together, and again Clare's need to be with people of her own age has been ignored.

After another 15 months the third bedroom now has a tenant, another young person, so at last Clare is feeling happier.

It feels like battling a system you don't really understand and often you don't know what is going on. If I could change one thing I would create a system where people could choose who they live with, instead of just meeting a stranger who is moving in.

By Marian Crawford

”



RESEARCH METHODOLOGY

Research was undertaken through a series of focus groups with parents and relatives of people with learning disabilities, and through two online surveys with both care professionals and parents.

Three focus groups were held in Petersfield, Nottingham and Richmond. In Nottingham, eight relatives attended, including parents and one sibling. In Petersfield, nine relatives attended, including in-law and step family members. In Richmond there were 11 attendees, consisting of parents of individuals with learning disabilities and a sibling. To support these three focus groups, a survey was also completed by 16 respondents who were parents or relatives of people with learning disabilities.

The online survey with care professionals was undertaken by 188 individuals.

FitzRoy developed this report with support from Forster Communications, a leading social change communications agency, working with clients to protect and improve lives. www.forster.co.uk.

CONCLUSION AND RECOMMENDATIONS

Parents of people with learning disabilities face the same issues and experience the same emotions that surround all parents, but it is simply much more acute. They are aware of the importance and reliance they have on external care and support for their loved ones, so when they have to struggle so hard to get the level of support they feel their children need, it is entirely understandable that they are desperately worried about what happens to their child when they are not in their corner constantly fighting for them.

Our research highlights the pressures these parents are under, and the anxieties they cause. It is clear we need to do more, and focus efforts and resource to relieve these pressures. We welcome the new provision for carers to have their needs assessed in the Care Act which came into force in April 2015. This new provision gives local authorities a responsibility to assess a carer's needs for support. We are concerned however, that not enough parents know about this change, and so are not taking up their right to an assessment. The second alarm bell is whether the increasing pressure on local government finances in this year's spending

review will mean these new rights fail to become a fully funded reality for carers.

As an organisation, we have long held the view that we should be considering the lifetime needs of a person with learning difficulties from the moment their needs have been identified. This research paints a picture of a system that is patchwork and short-term, despite the best efforts of the care professionals within it and the parents fighting so hard for their children.

Something that became apparent to us in creating this report is the lack of awareness of what the current options are for parents to ensure quality of life for their children when they are no longer around to support them. We want to make sure that this information is not only available but clearly summarised, accessible and that it reaches the people who need it.

We have developed three recommendations prompted both by the thoughts and ideas of parents and care professionals themselves and by our own consideration of the results of the research.

CONCLUSION AND THREE RECOMMENDATIONS

A WHOLE LIFE APPROACH

We are calling for local authorities to fulfil their duty of care by making provision for the potential lifetime needs, such as education, housing, employment, and medical care, for each person with a learning disability living within the local authority.

- This commitment will mitigate the anxieties and stresses the current short-term approach results in and provide reassurance to parents that their stipulations for the quality and type of care for their child will be adhered to, even after they've died.
- Lifetime planning will help local authorities tackle the short-term nature of the current system of support which our previous report, A Plan for Life, showed, costs more money and leads to breakdowns in care.
- A lifetime provision has the potential to deliver a more joined-up, integrated, approach between health and social care, bringing security and confidence to families.

RAISE THE STATUS OF CARE WORK

We want to improve the status of care work so that it more accurately reflects the skilled and vital work care professionals do.

- We are calling on the Government to run a campaign that raises the status of support workers and bring it in line with other professions. We want to change the perception that care work is an unskilled, low status career and industry. Increased social status will help stem the tide of care workers leaving the profession in favour of similar paid work in different sectors, like retail, or hospitality. By improving retention and morale in the sector, we will improve care for individuals and address one of the overriding concerns of parents.
- The legislation on a Living Wage is a welcome initial step in improving conditions for care professionals and we call on local authorities to ring-fence spending on learning disability services. This is essential if we are to prevent a race to the bottom, and enable care providers to pay the Living Wage as well as providing secure and stable care packages.

EMBED ADULT FAMILY PLACEMENT

We will work with local authorities to encourage and promote the innovative work being done through schemes like Shared Lives that match people with learning disabilities with people ready to share their home and provide care and support.

- We will work with local authorities to enable adults outside the immediate family to take on roles and responsibilities, and become a powerful advocate for individuals. This will enable individuals to secure the right care and support, provide the emotional support that many parents feel no-one but themselves can provide, and give parents the peace of mind that their son or daughter will be taken care of after they've died.



We can't make any of the recommendations a reality without the support of other individuals, charities, local authorities, and the social care sector more broadly, so we will be looking to work with partner organisations across the sector to help influence lasting change.

For further information and to get involved with our work please contact Diane French, Director of Operations and Business Development, diane.french@fitzroy.org

Follow our progress at www.fitzroy.org

FitzRoy
transforming lives



About FitzRoy

We are a national charity transforming the lives of people with learning disabilities.

FitzRoy supports people with learning disabilities to do the simple things that make a real difference to their everyday life. Our vision, mission and values guide us each step of the way, and are as important now as when the charity first began.

Our vision is a society where people are treated as equals, regardless of their disability. Our mission is to transform lives by supporting people with learning disabilities to lead the lives they choose.

FitzRoy
transforming lives

FitzRoy
transforming lives

Get in touch

FitzRoy House
8 Hylton Road
Petersfield
Hampshire
GU32 3JY

Tel: 01730 711 111
Email: info@fitzroy.org
www.fitzroy.org

Join the conversation



Report published November 2015

Registered charity number 1011290
A Company Limited by Guarantee
Registered in England, number 2699902

