

# STORIES FROM THE

# FRONTLINE

Thousands of people with learning disabilities rely on vital support services, which are under threat from the Government's spending cuts.



Learning  
Disability Coalition

# PROTECT THE FRONT LINE!

[www.protectthefrontline.org.uk](http://www.protectthefrontline.org.uk)

The **Learning Disability Coalition** represents 14 learning disability organisations who have come together to form one group with one voice.

The **Learning Disability Coalition** believes that people with a learning disability have the right to live independent lives with the support they need.

The members of the **Learning Disability Coalition** campaign to make sure that there is sufficient funding to enable people with a learning disability to have the same choices and chances as everyone else.

LDC members are: Association for Real Change, British Institute of Learning Disabilities, Down's Syndrome Association, Foundation for People with Learning Disabilities, Mencap, National Autistic Society, The National Forum for People with Learning Difficulties, People First, Real Life Options, Sense, National Family Carer Network, Turning Point, United Response and Voyage.



## MESSAGE FROM ANDREW LEE & MARK GOLDRING

Co chairs of The Learning Disability Coalition

### **Frontline services are at risk and thousands of people are in danger of losing crucial support.**

Against a backdrop of widespread spending cuts, we are hearing from local authorities who are facing tough decisions about how to allocate their money, as well as people with a learning disability and their families who are frightened that they are going to lose the care and support that they need to live their lives. Councils are already imposing efficiency savings, whilst at the same time they are faced by a rise in demand for social care services.

The **Learning Disability Coalition** is fighting to protect essential frontline services for people with a learning disability. To demonstrate the importance of these services, we have drawn together the stories of Tom, Kathryn, Mary, Hannah, James, Nicola and Leo to tell their **Stories from the Frontline**. Each person is unique in the support that they need and in how they use their services. They are united by the fact that without vital frontline support they would be facing cuts in their lives. Now more than ever, it is critically important that we protect the frontline.

*Andrew Lee    Mark Goldring*

# INTRODUCTION

In June 2010, the Government released its Coalition Agreement, where it committed itself to fairness in society, and dignity and respect for disabled people. It has since made a commitment to protecting frontline services, and supporting the most vulnerable people in our society. Thousands of people with a learning disability rely on these key frontline social care services to support their most basic needs such as bathing, dressing and eating. These needs, which once met, enable disabled people to live with dignity and respect and enabling them to participate fully in society. Frontline social care support services ensure that people are able to maintain their independence, go to work, and participate in activities in their communities. Crucially, this support allows people to access other services such as education, health and transport. Frontline services mean that people with a learning disability are able to live full lives.

Since before the 2010 general election, there has been talk of the necessity of cuts within public services. The threat of cuts to services is not just rhetoric; even before the announcement of the Emergency Budget and Comprehensive Spending Review, our research showed that 74% of Local Authorities were making efficiency savings and 10% were already being forced to make cuts to support services. The Learning Disability Coalition believes that support services are frontline services and that, as with the NHS, schools and foreign aid spend, they should be also protected.

This report asks what these cuts mean for the 1.5 million people with a learning disability and their family and carers when the Government has made a commitment to fairness in society, and dignity and respect for people with a disability. Cutting frontline social care support will be a direct betrayal of these promises, which were made to some of the most at-risk people in our society. Social care support is just as vital to thousands of vulnerable people as doctors and nurses are to those who are unwell.

In July 2010 the Learning Disability Coalition asked a number of families to keep a diary of their lives over one week, detailing the support that they received and the effect that it has on their lives. These diaries form our Stories from the Frontline and provide a crucial insight into the importance of frontline social care services and the devastating effect that cuts to these services have on the lives of people with learning disabilities and their families.

# METHODOLOGY

The Learning Disability Coalition asked 11 families to keep diaries of their week. Seven have been used in this report and the rest will be available on the Protect the Frontline website. The ages of our diary keepers ranged from 19 years old to over 50 years old and they were chosen to show the breadth of need for social services which exists in England today. We asked Luke Clements, Professor of Law at Cardiff University and human rights activist, to look at the diaries and examine what life would be like for our diarists without front line services.

This report also refers to a survey conducted by the Learning Disability Coalition, supported by the Research Group of the Association of Directors of Adult Social Services (ADASS). This was sent out in Spring 2010 to 154 Local Authorities and details the responses of 53 Local Authorities to ascertain the impact of funding cuts on people with learning disabilities and the funding pressures faced by Local Authorities.

Stories from the Frontline also draws upon a Learning Disability Coalition survey which was carried out in August 2010 of over 200 people with a learning disability, their families and carers in order to understand how people spend their time.

# SOCIAL CARE IS IN CRISIS

## 47% OF PEOPLE SURVEYED SPEND MOST OF THEIR TIME AT HOME

Learning Disability Coalition survey analysis: How do you spend your time?

To people with learning disabilities, social care is just as vital as health care is to people who are unwell. However, in comparison to healthcare and welfare, social care is vastly under funded. In 2009/10 in England, just over £16 billion was spent on social care, whilst £180 billion was spent on welfare and £110 billion was spent on healthcare. Since 1997 the Department of Health spend on social care has increased in real terms by 53%. But the spend on the NHS has increased by 100%, education by 60% and transport by 70%. The vast disproportion in the funding of social care is even more shocking when taking into consideration the strong evidence from the Kings Fund which shows that an increase in spend on social care for a person actually decreases the amount which needs to be spent on their healthcare.

There are over 1.5 million adults with learning disabilities in England, around 10% of whom are currently known to social services. This number is expected to increase rapidly by 2018, with the number of people with a learning disability needing support going up by more than 50%.

*“84% of councils described the funding situation for learning disability services in their area as difficult.”*

Social Care in Crisis: from the perspective of Local Authorities in England.

*“I anticipate that the situation will become more difficult in 2010/11 with in-house services being outsourced. The situation from 2011 onwards would indicate cuts in services.”*

Social Care in Crisis: from the perspective of Local Authorities in England.

There are a number of reasons for this dramatic increase in the need for social care services. Over 167,000 people with a learning disability are living with carers who are aged over 70, and as time goes on, both they and their carers will need support from social services in order to live their lives with dignity and respect. In addition to a high number of older carers, the number of people with complex needs is increasing, and this combined with longer life expectancy means that demand for social care services is rising and will be needed for longer. The number of people with learning disabilities who need services has been increasing by 3.5-5% per year, which is higher than had originally been estimated by the Government.

Without fair long term funding for social care, the services that are used by people with learning disabilities can only decrease as the demand increases. Social care is indeed a system in crisis.

*“Learning disability budget continues to experience extreme pressures, despite year on year increases for demographic pressures.”*

Social Care in Crisis: from the perspective of Local Authorities in England.



## TOM'S STORY

Tom is 24 years old, has a learning disability and is severely autistic. Two years ago, Tom left the Camphill Pennine Community where he had been going to college, and his parents, on the recommendation of the council sought to get Tom an individual budget so that he could move into supported living. Tom eventually moved into his own house where he now receives 24/7 support. This move was only possible due to the hard work and funding of his parents who arranged a family funded shared ownership alongside Advance Housing and the Department of Work and Pensions. Tom's family have had a very difficult fight to get him the support that he needs and have described how frustrated they have been and how hard they have had to work to get Tom the necessary support. Tom has also experienced difficulties with the lack of consistency in his funding and this has caused him to become stressed and confused which places further pressure on his family. At the time of writing, Tom, after two years was still in receipt of a temporary budget from his local authority and having to use his Disability Living Allowance, mobility benefits and money from the Independent Living Fund to contribute to the cost of his care.

› **MONDAY** I got up at 7.30 am and played my music. My support worker prompted me to use the bathroom, get dressed and helped me to make my breakfast. I cleared away my breakfast things by following a chart made by my speech and language therapist.

› **TUESDAY** I went with my support worker on the supertram to the gym at Pond's Forge baths and sports centre. I got cross with my support worker when he tried to make me work harder. I go to the gym every week – I don't always enjoy it, but it is part of my weekly routine so it makes me feel secure.

› **WEDNESDAY** This afternoon, Elaine, my mum's best friend, came to see me. Mother and Father are on holiday this week, so Elaine took me to the pub, where I had a burger, chips and onion rings (never vegetables) and an ice cream, and two shandies. Elaine is a very kind lady, and she always comes to see me when my parents are away.

› **THURSDAY** Today, I did my weekly shop at Sainsbury's, and the butcher. The people know me in both shops. My support worker helped me with my shopping, and to stay calm because if I get worried I try to leave without paying or taking my shopping. My support worker helped me with money and change, because I don't understand it. In the evening I rang my sister. I ring her every Thursday. I love her very much.

› **FRIDAY** Today I went to both morning and afternoon art classes. I enjoy them a lot, but they are very expensive. My Mother and Father may have to pay for it soon as it is £60 per week. I took a packed lunch to the art class, but the canteen was too crowded for me, so I got scared and ran away. My support worker was watching and bought me back. I was upset so I locked myself in the toilet until the afternoon class.

› **SATURDAY** My sister Hanna took me to town and to Meadow Hall. This was to spend £50 that I won in my housing association prize draw. I was very lucky to go to both places in one day. I bought music and pre-school DVDs. I had a lovely day, and when Mother and Father rang me in the evening, I was very excited when I told them about my day.

› **SUNDAY** I usually go to the cinema on Saturday mornings. I find what I want to watch on the internet on Friday evenings. Because I was with Hanna yesterday, my support worker took me on Sunday instead. I saw Toy Story 3, which was good.

## LUKE SAYS:

Without this care, it is clear that Tom would not survive. He would be entirely dependent on his family, and forced to spend the majority of his time in the family home, where he would be unable to participate in his community or take part in any of the activities which he loves.

Professor Luke Clements, Cardiff University



Image: Mencap 2010 (for illustrative purposes only)

## KATHRYN'S STORY

Kathryn is 33 years old, and has profound and multiple learning disabilities. She lives at home in London with her mum, Dorothy. Kathryn receives an individual budget from her Council. Since Dorothy set up her care team, Kathryn has had a team of support around her, including carers and support workers. However, her mum and her sister, who is a trained occupational therapist provide Kathryn with a great deal of support, but do not get paid. Dorothy also spends a large amount of time and effort managing Kathryn's individual budget. Kathryn needs and likes, structure and consistency in her life and the difference in having a well run team in her life has been life changing for both and her mum. Here Dorothy explains what a typical week looks like for her and her daughter.

► **MONDAY** On a typical day I get Kathryn up when she wakes between 7-10 am. I take her to the toilet, make a cup of tea, administer her medication and start breakfast. Today, at 10 am our first support worker arrived and stayed with Kathryn until 4 pm. She gave Kathryn her shower, cleaned her teeth and got her dressed.

► **TUESDAY** Kathryn and her support worker went out to the local park in the afternoon, where they met the next support worker who brought Kathryn home. They spent the afternoon playing with playdough, listening to music and reading stories. Even if Kathryn was happy leaving the house twice in one day, there are no evening activities available which meet her particular needs

► **WEDNESDAY** Kathryn's sister, Charlotte, arrived. She is a qualified occupational therapist, so the input she provides is very valuable. We have very rarely received occupational therapy from the local authority – perhaps once in fifteen years.

► **THURSDAY** Kathryn stayed with Charlotte until 4 pm. They spent the day doing some home-based activities and usually attempt to walk to the local park, where they might have a picnic. Kathryn's day time activities depend very much on her autism as some days her difficulties are impossible to surmount.

► **FRIDAY** Kathryn's support worker arrived at 10 am, and brought the masseur with her. They did activities at home until the afternoon when they took public transport to Southbank to meet the next support worker. It is the summer holidays so it's very busy and noisy which can be really distressing for Kathryn.

► **SATURDAY** The first support worker arrived at 11 am, and stayed until 5 pm. She usually takes Kathryn to the local market or park. The rest of the afternoon and evening was spent with another support worker at home. Her support worker helped to prepare her dinner, bathed and ready for bed. Often Charlotte will come over to do another sleep over.

► **SUNDAY** I rarely get any support on a Sunday. We spent the day going to the local shops and the park and stayed at home listening to music in the afternoon.

## LUKE SAYS:

Kathryn's mum cannot be paid for the care she provides and so if a breakdown occurred, without suitable emergency or local support, Kathryn could end up in a very expensive residential care home, miles from her friends and family

Professor Luke Clements, Cardiff University

# CUTS ARE ALREADY HAPPENING

Local Authorities have already been making significant efficiency savings, and many have already been forced to cut services. The Government's proposed cuts of 25-40% are simply unsustainable for social care. The responses to the Learning Disability Coalition's Social Care in Crisis survey revealed the impossibility of reducing expenditure to this extent without cutting into direct services, and as one Local Authority said "Our 4 year medium term financial strategy is scored on 20-25% savings given projected shortfalls in Government funding. This cannot be achieved by efficiency savings." The recent demands to reduce expenditure further need to be set against the current situation where 74% of local authorities are already making efficiency savings, and 10% of Local Authorities are already cutting services.

Local Authorities are likely to be further affected by the freeze on Council Tax, promised by the Government. On average 39% of Council Tax revenues are currently used to support adult social care. In some areas this figure is as high as 80%. Freezing Council Tax will have a direct negative impact on social care budgets and is likely to contribute to a situation where further cuts become likely.

*"I watch telly because there is nothing else for me to do as I need support to go out and only receive 4 hours support a week"*

Learning Disability Coalition survey analysis: How do you spend your time?

# ONLY 3% OF LOCAL AUTHORITIES FELT THAT LEARNING DISABILITY SERVICES WERE WELL-FUNDED, WHILST 84% DEEMED THE FUNDING SITUATION AS DIFFICULT.

Social Care in Crisis: from the perspective of Local Authorities in England.

Cuts to social care services have are occurring in a number of ways. Currently, three quarters of Local Authorities are only supporting people with critical or substantial needs. At the time of going to press, at least 3 Local Authorities were consulting on changing their eligibility criteria and reducing the number of people they support. This creates an unfair postcode lottery system and the Local Government Association has warned that from 2011 many Local Authorities will only be able to support people with critical needs.

Cuts are happening to a system that is already in crisis. There continues to be a need for reform of services in order to deliver the aspirations of policies including Valuing People Now. Efficiency savings and cuts are actually preventing this necessary change from happening. Whilst there is scope for more cost effective models of provision improved value for money will not in itself be sufficient to solve the funding crisis.

One Authority stated that "If, after meeting critical and substantial needs, additional resources were available, the following areas would be a focus- Improved support for people with mild and moderate needs- low level interventions which will delay the needs for more intensive and costly social care services and enable people to maintain their independence."

*"I do not go out now as only my foster dad is alive now and I need 2:1 care when in all public places".*

Learning Disability Coalition survey analysis: How do you spend your time?



## MARY'S STORY

Mary is 46 years old, and lives in a residential care home with five other people. As her diary shows, Mary has a very busy and social week. She visits her day centre almost everyday and has many friends there. She takes pride in her appearance and is very close to her support workers. Without support Mary would lose access to many of the services that enable her to live a full happy life.

► **FRIDAY** My support worker woke me up and assisted me to have a bath and get dressed. She then helped me to have my breakfast. Later she took me by car to Heatherfields, my day centre, where I was greeted by my friends and we sat on the sofa and had a cup of tea. I enjoyed listening to them chatting. Later in the day, Carole did my nails in a very nice shade of pink.

► **SATURDAY** I had a lovely day out with Helen, Malty and Carole at Whitby. We walked along the pier which was lovely and refreshing then went to the Magpie for fish and chips. We then went to Sandsend to eat them, and we had a walk along the beach front.

► **SUNDAY** I had a sleep in today until 11 am, Eileen my support worker, took me to have my hair dyed in the bathroom and gave me a bath; she was singing to me while she assisted me. I had my hair washed, my teeth brushed and help to put my PJs on, and then I had my hair blow dried and sat in the lounge to have my supper. Eileen put me to bed - I had a very nice pamper day and was asleep by 10 pm.

► **MONDAY** I spent the day at Heatherfield's and for dinner I had jacket potatoes with tuna and salad. I was tired this morning and didn't really do very much but I brightened up this afternoon and played bingo with help from the staff.

► **TUESDAY** I went to Teeside Park and with support I bought some new hangers for my clothes. I helped my support worker to hang up my clothes. I got ready for bed and had crumpets and tea for supper. I then sat in the lounge and then went to bed with help from my support worker.

► **WEDNESDAY** When I came home from Heatherfields, I was supported by Leigh to have a cup of tea and sit in the lounge. I fell asleep on the sofa for a while. After waking up, Elizabeth assisted me to have my tea which I enjoyed. I had a lovely bath after my tea, was supported with my personal care by Kerry who also helped me to get dressed. I had a sit in the lounge for a short while and a walk around the house. I got ready for bed with support and enjoyed my supper of tea cakes and Horlicks.

► **THURSDAY** I arrived at Heatherfields and was greeted by all my friends. I went out to Strikes Garden Centre for a walk around and had a look at all the plants and fish. I had a scone with jam on and a cup of juice. I arrived back at Heatherfields in time for lunch which I ate with support.

## LUKE SAYS:

Mary's support workers help her to bathe, dress and eat. If this essential lifeline was missing, Mary would have great difficulty in managing her personal care and her hygiene would deteriorate. Without regular healthy eating she would be more likely to end up malnourished and unwell

Professor Luke Clements, Cardiff University



Image: Mencap 2010 (for illustrative purposes only)

## HANNAH'S STORY

Hannah has very complex needs and is also deaf blind. She lives in a residential college all year round where she has one to one support all day, and staff to watch her during the night. Here, with the help of her support worker, Kara, Hannah describes her week.

► **MONDAY** In the morning, the staff used a number of different sensory techniques to help me wake up, including music and switching on and off the light. A staff member prepared my medication and showed me a communication book which explained what I was going to do during the day. I was helped to have a shower and get dressed.

► **TUESDAY** This morning I had a lesson at college in life skills. One of my main targets was to learn how to make a sandwich. I chose what I wanted in my sandwich, but I needed help to find the fridge and the bread. I also needed hand over hand support to butter the bread and cut the cheese.

► **WEDNESDAY** Today I had an appointment at the local hospital which required two support staff to go with me. After going to the hospital, I was supported to participate in a music session at college, which I really enjoyed but I needed some help to stay focussed.

► **THURSDAY** Today was a very busy day for me as I went with some friends to a local cinema to watch a short film made by the college students. I really enjoyed this. When I came home, I was helped to prepare for the college prom. My behaviour became quite challenging as I was a bit reluctant to let the staff to help me to get ready. When I got to the prom, I had a seizure which meant that I needed rescue medication and had to be taken home to recover.

► **FRIDAY** I went for a picnic with some other students and I had a great time! Whilst I was at the park, I had another seizure which required medication and left me feeling very tired and shaky. The college staff took me home, so that I could sleep until I felt better.

► **SATURDAY** Today was a very special day for me and the other students at the college, as there was an end of term visit to a local theme park. I was really excited about going, and with one-to-one support, I was able to go on all the rides that were appropriate for me.

## LUKE SAYS:

Hannah has complex medical needs which the staff at her college are trained to deal with. This means that if she has a seizure, she can often be looked after at home. If the support she receives from trained staff was cut she would need more costly medical care in hospital

Professor Luke Clements, Cardiff University

# CUTTING NOW COSTS MORE LATER

There is considerable evidence to show that making cuts now will mean increased costs in the future. For example, research into the Financial Benefits of the Supporting People programme 2009, shows that a cut in the Supporting People Programme increases the cost to the NHS of a person with a learning disability being admitted to hospital with a general health issue from £1,537 to £3,236.

Cutting social care services has a direct negative impact on people's health and well being and increases financial pressures on the NHS. Taking services away from people will often result in a crisis situation which is far more costly in the long-run than low key preventative care. Failure to provide support to people with a learning disability increases the risk of social exclusion and health problems, particularly mental illness. This can lead to the need for expensive acute intervention when the person reaches crisis point.

*"8 out of 10 families have reached breaking point as a result of not getting the help and support they need"* Mencap 2006

## 51% OF PEOPLE SURVEYED SAID THAT THEY FEEL LONELY AND 64% DO NOT GET TO SEE THEIR FRIENDS AS OFTEN AS THEY WOULD LIKE

Learning Disability Coalition survey analysis: How do you spend your time?

In a survey carried out by Leonard Cheshire Disability, 82% of people said that a shortfall in their care package had adversely affected their mental health and sense of well being, whilst 52% said that it caused more accidents, serious illness, attempted suicide and more visits to the doctor and hospital.

The extra strain caused by inadequate care packages is not only felt by the person with disability but also by their families and carers with 14% concerned about increased illness, accident and stress to their carers.

The King's Fund has made a persuasive case that transferring 1% of funding each year from NHS to the social care budget would avoid much bigger costs for the NHS. The Learning Disability Coalition understands this proposal to be a robust means of ensuring that social care support is properly funded.

*"35% of respondents who had lost their social care services had gone into debt paying for their care."*

Your money or your life, Leonard Cheshire Disability, 2008



## JAMES' STORY

I live in my own specially adapted bungalow, where I have been living independently for two years. I need 24/7 support because of my severe disabilities. I get this support through a combination of agency support workers, and my mum.

## LUKE SAYS:

Without the support that James receives his parents would lose their peace of mind and once again become his primary carers, whereas now they know that he is happy and safe, is able to take part in the local community and is able to enjoy just being himself

Professor Luke Clements, Cardiff University

› **MONDAY** My mum woke me up this morning, and supported me to have a shower, get dressed and get into my wheelchair, ready for breakfast. I helped my mum to prepare my breakfast. After this the minibus and escort, Joyce, arrived to take me to my day centre. In the day centre I have two care assistants, Jo and Sarah, who help me with my personal hygiene and who help me to take part in activities like music therapy which I really enjoy.

› **TUESDAY** Today is a very special day as it is my Dad's birthday. My support worker, June, took me to my parent's house where I joined in with a family meal and birthday cake. Mum had helped me to choose and wrap some presents, and my sister helped me to give Dad his presents and card. I watched Dad open his presents and was very happy.

› **WEDNESDAY** Mum and June took me to the day centre where I had a quiet day because I was feeling quite ill with a wisdom tooth coming through. When I came home, Mum and I went into the garden to sit in the sunshine, and she helped me to re-order my medication and incontinence aids. I went to bed very early as I was tired, and Mum stayed with me throughout the night.

› **THURSDAY** Today I went to Worester Snozelen, a multi-sensory centre which helps me to explore the world around me in my own way. My favourite activity is the Star Tunnel, which is a completely dark room with lots of sensory things, like stars and lights. Jo supported me to explore the Star Tunnel, before I went back to the day centre where she attended to my personal care and fed me lunch.

› **FRIDAY** This afternoon my support worker, John, and I went to the local park for a picnic. He prepared my tea and drove us there. When we arrived, John got me out of the car and supported me to feed the ducks and pushed me around the park. After he had fed me my tea and medication, we went home, where John supported me to have a shower and got me ready for bed.

› **SATURDAY** John and I spent the day exploring a sensory garden, and going for a walk along the local canal to watch the barges. When we returned home my new support worker, Jono, was waiting for us. Today was the first time that Jono was going to support me by himself. My care is very complicated, so Jono has had a lot of training to make sure he knows how to look after me properly.

› **SUNDAY** Jono woke me up at 8.15 am, and he washed and shaved me, and then hoisted me into my wheelchair. June arrived and shadowed Jono feeding me my breakfast and giving me my medication. June helped me to get ready to go out, and then took me to my local church, where I met up with some friends.



## NICOLA'S STORY

Nicola lives in a residential home with nursing care. The staff are trained to meet all of her needs including carrying out personal care, maintaining her feeding tube and monitoring her epilepsy. Nicola has 24/7 care, as her needs are very complex. Before this she lived at home and attended school.

## LUKE SAYS:

Nicola's story shows how the right support can prevent emergency situations which are extremely distressing and may require expensive medical care. Nicola's health needs change daily and if the nursing staff and support workers, who are extremely important to her were to be reduced, the flexibility needed to make sure she receives the best care from people who understand her needs would be severely reduced.

Professor Luke Clements, Cardiff University

➤ **MONDAY** This morning I was assisted with my personal care, including washing, dressing, teeth cleaning and hair brushing. I was assisted to the sofa where I was given my medication and feed. My nasogastric tube has to be checked regularly by a qualified nurse who makes sure that it is in the correct position.

➤ **TUESDAY** Today I went shopping with my mum, and a support worker. Another member of staff came with us to drive the specially adapted minibus. We drove into town and went into a number of different shops to try and find me a new dress. My mum and support worker showed me a few different items, and chose a dress for me which they lay on me to see if it fitted. It would have been impossible for me to try it on in the shop.

➤ **WEDNESDAY** I was feeling very tired from yesterday so I had a lie-in, and when I woke up I was feeling a bit unwell, so I was hoisted onto the special sofa, where I was given some passive physiotherapy which helps me in draining off excessive secretions.

➤ **THURSDAY** I needed a lot of support today as my breathing was laboured and I felt very ill. Someone had to stay with me at all times, and I needed a lot of support from the staff.

➤ **FRIDAY** This morning, I needed physiotherapy which was given to me by a trained support worker. Later, I was visited by my epilepsy consultant.

➤ **SATURDAY** I got up very early this morning, and was assisted to have a really relaxing bath. I was very excited and giggly this morning because I am going to go out with my family tonight. A support worker came with me, another drove the minibus and I had a lovely family outing at an Indian restaurant, and was laughing and smiling all the time. I was able to stay out until 12pm, as the minibus driver swapped her shifts around so that she could collect me later. When I came home, I was assisted to bed by the two night staff.

➤ **SUNDAY** I had a very lazy morning as I was tired from being out so late the night before. When I woke up I was assisted with all my personal care, and was given my food and medication. I spent the afternoon relaxing by lying on my bed and watching a DVD. I was checked regularly by a support worker or a nurse to make sure that I was alright. I was put to bed by the two night staff.

*"It is inevitable that high placement care package costs will need to reduce. The challenge is to do this without compromising quality and with the full consent of service users and carers"*

Social Care in Crisis: from the perspective of Local Authorities in England.



## LEO'S STORY

Leo is 19 and lives in Cornwall with mother, Cayce. He experiences severe autism and is accompanied at all times for safety's sake, whether by Cayce or trained support workers. 18 months ago, Leo received very little social care, leading to hardship and serious problems for both Leo and Cayce, but this began to change after Cayce fought to receive a better service. Now, Leo says "My Mum and I have been able to start a real life like everybody else." Here, Leo records his week.

› **MONDAY** Mum helps me get up, wash, dress, shave, have breakfast and get ready to go to Boscawen farm, where I learn about farming, social skills and work. My support workers helped me join in with the farmyard tasks, watering plants, cleaning the feed store and helping repair a tractor. I love the farm, but without my support workers I wouldn't be able to join in safely.

› **TUESDAY** Today I went to school at Three Bridges. I do lots here, including arts and crafts, numeracy, literacy, computing, cooking, dog walking and visiting places. I have been at Three Bridges for 18 months and grown very fond of the staff. I have learned to trust them and to listen, to follow instructions as well as to make decisions for myself.

› **WEDNESDAY** My mum came to provide extra support to go to the cinema with a group of students and teachers. The cinema is a new experience and I am proud of myself for participating in this new activity so well. When we got home a support worker helped me cook dinner, make models and walk a neighbour's dog. My neighbour is my friend. She's old and had a big operation recently so it's hard for her to do it herself at the moment. With support I can do my bit too.

› **THURSDAY** Today support workers helped me go to the big supermarket. Together we made a shopping list, which I found difficult, but with help from my support workers I managed. We discussed what money I would need. My support workers help me to find everything, and then I put it through the self-service checkout. I liked that.

› **FRIDAY** Today was my school celebration day, so I was in a good mood and very excited. My support worker helped me to get ready, including shaving. There was a buffet which I helped to prepare and I got two achievement certificates and a gift voucher.

› **SATURDAY** After a lazy morning we went out for a long walk around my local area and as usual I chatted to all the shopkeepers, tourists and locals we met along the way. If I ever need any help interacting with people my support worker is able to do that, but usually I like to be independent and express myself in my own way.

› **SUNDAY** Today my mum helped me get ready. Sunday morning is usually when my mum and I do the washing and tidying the flat, though I do not like to do this! We hoovered the flat, took the rubbish out, washed up and cleaned the bathroom. Later, me and my support worker went to the local older people's care home which I visit once or twice each week to help out with a bit of hoovering, cooking or chatting to the residents there. I like doing this as it feels like having a real job.

## LUKE SAYS:

Without support, neither Cayce nor Leo would be able to plan for the future; the idea of Leo playing a part in his community or getting a job would go back to being distant dreams.

Professor Luke Clements, Cardiff University

# A CUT IN SERVICES IS A CUT IN LIVES

Professor Luke Clements

**The stories of Tom, Kathryn, Mary, Hannah, James, Nicola and Leo make it clear just how important frontline care and support is to people with a learning disability and their families. This support helps to meet people's most basic care needs, such as eating, dressing, bathing and staying safe, but more than this, it allows people to live their lives rather than just existing.**

For Tom, the care and support he receives allows him to live independently from his parents and be an active member of his community; just like any other 24-year old. He is able to go to the gym, art classes, eat out, go to the cinema and hang out with his sister. Tom's family still provide him with a considerable amount of support and funding, but they are no longer his primary carers which means that as his parents get older, they do not have to live in fear of reaching a crisis situation and Tom's sister is able to enjoy her life too instead of feeling under pressure to be his carer.

Without this care, it is clear that Tom would not survive. He would be entirely dependent on his family, and forced to spend the majority of his time in the family home, where he would be unable to participate in his community or take part in any of the activities which he loves.

Similarly, if the minimal support which is provided to Kathryn and her family were cut further, this could result in her mother reaching breaking point and them both needing much more expensive provision in the future. There are few services which Kathryn actually receives at the moment. People with profound and multiple learning disabilities need specialised services and these do not exist locally. The main service Kathryn needs is respite care and she has to go to North Yorkshire for this.

The other service Kathryn uses, is 'continuing education', and she was recently given a space at Orchard Hill, after being on their waiting list for 7 years. This service is already being cut; the first year she had two days a week, and in 2010 it was cut to one day a week. If this is cut further, her mum, who is already over-stretched, will have to provide other activities in the home for Kathryn which may end in breakdown. If a breakdown occurred Kathryn could end up in a very expensive residential care home, miles from her friends and family.

Mary's support workers help her to bathe, dress and eat. If this essential lifeline was missing, Mary would have great difficulty in managing her personal care and her hygiene would deteriorate. Without regular healthy eating she would be more likely to end up malnourished and unwell. If her access to transport was to stop, Mary would not be able to get to and visit her day care centre or go out on the day trips she speaks of so fondly. She would end up staying at home all day, every day and be at serious risk of becoming isolated and depressed. It would be a similar risk if her day centre were to close. It provides Mary with a safe and secure place for her to meet and socialise with her friends as well as giving her support workers a rest.

If Hannah's support was cut she would be prevented from building up skills which will help her for the rest of her life. This placement makes a huge difference to Hannah, and without it her family would lose the peace of mind they have when they see how settled she is. Hannah receives communication support, without which she would have difficulty expressing her needs and would become increasingly isolated. As well as having a learning disability, Hannah has complex medical needs which the staff at her college are trained to deal with. This means that if she has a seizure, she can often be looked after at home. If the support she receives from trained staff was cut she would need more costly medical care in hospital.

# CONCLUSION

The support that James receives is vitally important as it allows him to be cared for 24/7 and live independently from his Mum and Dad. His parents had to work really hard to get the right support for him, and before he was given an Individual Budget, they really struggled to make sure that he had the right care. James' mum has been his main carer for twenty-five years, but now that James is properly supported, she has been able to return to work where she can help others with personalisation and support. Without the support that James receives his parents would lose their peace of mind and once again become his primary carers, whereas now they know that he is happy and safe, is able to take part in the local community and is able to enjoy just being himself.

Nicola's story shows how the right support can prevent emergency situations which are extremely distressing and may require expensive medical care. Nicola's health needs change daily and if the nursing staff and support workers, who are extremely important to her were to be reduced, the flexibility needed to make sure she receives the best care from people who understand her needs would be severely reduced.

Without the care and support that Nicola receives her family would be constantly worried as to her well being. Nicola's life would be much more restricted and she would not be able to go to concerts and shows as well as on holidays, which she really enjoys. Her family are delighted with the support that Nicola receives, and seeing how settled and happy she is means that they are able to enjoy being a family again without having to worry about the future.

For Leo and his Mum, Cayce, finally getting the support that they had needed has been life transforming for them both. As Cayce says, before she had adequate support, she found herself "despairing for our future". If frontline support was taken away again, she would be responsible for all aspects of looking after Leo, with no time for her own life or needs. Without specialist support, it would be difficult for Leo to progress: as he says of two years ago, "I stopped growing, my behaviour and moods were always challenging, and I was very difficult to keep safe". Without support, neither Cayce nor Leo would be able to plan for the future; the idea of Leo playing a part in his community or getting a job would go back to being distant dreams. When Leo thinks back over the years that he and his Mum were without support, he says that "it felt like I didn't really have a life, it was just existing."

The Government has made a commitment to fairness, dignity and respect for people with a disability - cutting critical frontline services is not fair and does not offer dignity and respect. Without frontline social care support, people will not be able to meet their most basic needs such as eating, personal hygiene, dressing, keeping safe and having somewhere to live. These diaries show that people like Tom, Kathryn, Mary, Hannah, James, Nicola and Leo would end up with a life less than ordinary. These diaries show only 7 people's lives. There are 141,000 people with a learning disability who are at risk of social care cuts. Our survey shows that people with a learning disability are bored, lonely and isolated. They rarely get an opportunity to see their friends or a chance to fulfil their aspirations.

Further cuts are not inevitable in social care support. For the Government and Local Authorities questions of priorities need to be asked and decisions need to be made. The case for protecting frontline social care support is compelling. Each cut in a service, is a cut in the lives of the person who once used it. Social care is as vital to many vulnerable people as doctors and nurses are to those who are unwell. We call on the Government to help protect fairness, dignity and respect for all disabled people. We ask the Government to protect the frontline.

## CALL TO ACTION

**Help protect the frontline, go to  
[www.protectthefrontline.org.uk](http://www.protectthefrontline.org.uk)**

# BIBLIOGRAPHY

ADASS (2010)

**All you need to know about adult social care: Facts, figures and the challenges to come**

Cabinet Office HM Government (2010)

**The Coalition: Our Programme for Government**

Carers UK (2009)

**Policy Briefing: Facts about carers**

Department of Government and Local Communities (2009)

**Research into the financial benefits of the supporting people programme, 2009**

[www.communities.gov.uk/documents/housing/pdf/1274439](http://www.communities.gov.uk/documents/housing/pdf/1274439) [August 2009]

Department of Health (2008)

**Valuing People Now: From Progress to Transformation**

Emerson, E. & Hatton, H. (2008)

**'People with Learning Disabilities in England', Centre for Disability Research**

[www.lancashire.gov.uk/office\\_of\\_the\\_chief\\_executive/lancashireprofile/jsna/documents/LearningDisabilitiesEngland.pdf](http://www.lancashire.gov.uk/office_of_the_chief_executive/lancashireprofile/jsna/documents/LearningDisabilitiesEngland.pdf) [December 2009]

Learning Disability Coalition and the Association of Directors of Adult Social Services (2010)

**Social Care in Crisis: from the perspective of Local Authorities in England**

Learning Disability Coalition (2010)

**Survey Analysis: How do you spend your time?**

Leonard Cheshire Disability (2007)

**Your Money or Your Life**

The King's Fund (2009)

**Briefing: Funding adult social care in England**

The King's Fund (2010)

**Parliamentary Briefing the Emergency Budget: Health and Social Care**

National Audit Office (2009)

**Supporting people with Autism through adulthood**

Mencap (2006)

**Breaking Point**

# ACKNOWLEDGEMENTS

The Learning Disability Coalition would like to thank Tom, Kathryn, Mary, Hannah, James, Nicola and Leo, their families and supporters who have contributed their stories to the report.

Thank you to the people with learning disabilities and their carers who completed the Learning Disability Coalition's online survey.

Thank you to the contributors to Stories from the Frontline – Professor Luke Clements, Laura Smith, Jacqueline Maher, Jaime Gill, Esther Foreman, Anthea Cox, Linda Byrne and Rachel Bowen.

Some of the names of the people in this report have been changed.

# PROTECT THE FRONT LINE!

Show your support by calling on Local Authorities and Central Government to promise that if tough spending choices have to be made, then the funding for learning disability services must be protected against any cuts.

I (insert name), \_\_\_\_\_ pledge to 'Protect the Frontline'.

Please send me details on what I can do to help.

Name: \_\_\_\_\_

Email: \_\_\_\_\_

Address \_\_\_\_\_

Postcode \_\_\_\_\_



By filling out your details above, you have agreed to receive email updates from the Learning Disability Coalition.

If you do not want to be contacted in this way, please tick here

**Freepost RRRT-YRBT- XKSH  
The Learning Disability Coalition  
123 Golden Lane  
London, ECIY 0RT**