

PRESS RELEASE

EMBARGOED UNTIL 0001AM, WEDNESDAY 26 JULY 2017

JO WHILEY HELPS LAUNCH NATIONAL PETITION TO SAVE HER DISABLED SISTER'S SUPPORT AND THOUSANDS OF OTHERS

- **PLEASE READ THE STORY OF FRANCES, SISTER TO BBC RADIO 2 PRESENTER JO WHILEY AND [SIGN OUR PETITION](#)**

Royal Mencap Society (Mencap) today (Wednesday) launched its **#StopSleepInCrisis [National Petition](#)**, asking members of the public to support its campaign to protect the vital sleep-in service for adults with a learning disability.

Launching the Petition, Mencap CEO Jan Tregelles, said:

“Sleep-ins are widely used in the learning disability sector to provide essential care for vulnerable adults in their own homes, in the communities where they live.

“For a person with a serious learning disability having someone stay overnight ‘at home’ makes the vital difference between ‘living a life’ and spending the rest of their life in a hospital setting.

“But don’t listen to me, let me share Frances’ story, told by her sister, presenter, broadcaster and Mencap Ambassador, Jo Whiley”.

Frances’s Story

Two years ago my family were in crisis. My sister Frances who has learning disabilities had a breakdown and had to be sectioned. We don't know why, we don't know what brought it on - we didn't know what to do, we were absolutely desperate. I wonder if it was a subconscious break out for independence - that at the age of 47 she didn't want to live with my parents anymore, she wanted to be allowed to grow up and live as an independent adult.

Frances has always had sleep issues. For as long as I can remember she simply hasn't wanted to go to bed and could go for days and nights without sleep which is fine, it's just that she wouldn't let anyone else sleep either. We used to tell her stories all night long, if you dared to fall asleep you'd be woken with a hefty smack to the head. We tried everything - but she was pretty destructive.

She tore up curtains, wallpaper and bedcovers - overturned her bed so we had to nail it to the floor. She'd paste the walls in turn with whatever she could, vomit, urine, faeces. Her room was a battle zone. She moved to a residential home where everyone worked tirelessly on her sleep issues. To no avail. At one point she managed to break open a window and climb out. The first staff knew about it was when she walked in with a broken hip asking for a cup of tea!

Thirty years on and Frances is older and wiser but still has issues with sleeping at night. After her breakdown when she was sectioned, she moved into a Mencap house where they have worked hard to help her settle. She often refuses to go to bed and will prefer to sleep downstairs rather than in her own bed. She's strong and

loud and it's impossible to placate her when her mind is made up about where she wants to sleep for the night but at least she has a home where she is happy and settled.

The only way Frances is able to live in her new home rather than with my parents is because she is cared for by Mencap staff who sleep in overnight. If they weren't there, she would simply escape from the house and who knows what would happen? She has little road awareness and would simply disappear into the night and into danger.

I cannot emphasise enough how crucial sleep in care staff are to Frances' safety and wellbeing. They make a vital difference and enable Frances to live an independent life. She could never go back home to live with my parents - they simply couldn't cope and nor could she.

It's been a long painful journey for everyone to get her to where she is today - living independently but happily and safely. I'm scared that the Government's failure to grasp the nettle on a critical funding issue like payment for sleep in care staff will jeopardise her future.

*Please support the Royal Mencap Society's **#Stopsleepincrisis** Campaign and sign our on-line petition which is going live today.*

Commenting on Frances' Story, Mencap Chairman Derek Lewis, said:

“There are 178,000 people in our society, like Frances, very many of whom desperately need sleep-in support.

“Unfortunately, recent Government changes to the interpretation of the law on pay for sleep-ins has created a £400 million demand for back-pay from HMRC that providers are unable to meet. Many face insolvency and the continued care of Frances and many others is at risk. Ordinary families who pay for care of a loved one with a personal budget could also be hit with back-pay demands.

“This isn't a question of Mencap not wanting to pay extra money to its staff. Our social care colleagues do an outstanding job, but we cannot pay them if we do not have the money and we only receive money from Government sources for sleep-in support.

“Government has a legal and moral obligation to fund the social care of those with serious learning disabilities. Finding a solution to this problem, after months of discussion, should be a top priority for any caring Government. The clock is ticking.”

Please sign our petition to the Prime Minister to stop irreparable damage to an already fragile sector of our society and spread the message on line using the **hashtag #StopSleepInCrisis**.

[Please click here for a link to the petition.](#)

Look out for our **Mencap Ambassadors** who will be spreading the message far and wide.

Please help us keep people with a learning disability safe.

-ENDS-

For further information or to arrange interviews, please contact the Mencap press office on 020 7696 5414 or media@mencap.org.uk or for out of hours 07770 656 659.

Notes to editors

Royal Mencap Society issued a news release on Wednesday 19 July 2017. For further detail to the story please visit this link <https://www.mencap.org.uk/press-release/royal-mencap-society-chief-urges-government-avert-crisis-learning-disability-sector>

About Mencap

There are 1.4 million people with a learning disability in the UK. Mencap works to support people with a learning disability, their families and carers by fighting to change laws, improve services and access to education, employment and leisure facilities. Mencap supports thousands of people with a learning disability to live their lives the way they want.

www.mencap.org.uk

For advice and information about learning disability and Mencap services in your area, contact **Mencap Direct** on 0808 808 1111 (9am-5pm, Monday-Friday) or email help@mencap.org.uk

What is a learning disability?

A learning disability is a reduced intellectual ability which can cause problems with everyday tasks – for example shopping and cooking, or travelling to new places – which affects someone for their whole life.

People with a learning disability can take longer to learn new things and may need support to develop new skills, understand difficult information and engage with other people. The level of support someone needs is different with every individual. For example, someone with a severe learning disability might need much more support with daily tasks than someone with a mild learning disability.

Learning disability is NOT a mental illness or a learning difficulty. Very often the term 'learning difficulty' is wrongly used interchangeably with 'learning disability'.