# Eden’s story

This story was used in a campaign to get homes in the community near their friends and families for people with learning disabilities who are living in institutions far from their homes. This link tells you about the campaign <https://theatuscandal.wordpress.com/2016/04/>



Eden is 24. He has two labels: ‘moderate learning disability’ and ‘autism’.

In 2016 Eden had been in Assessment and Treatment Units for people with learning disabilities (ATUs) for seven years. This is a type of institution.

Eden went into the first ATU when he was 17.

He was there for 5 years.

He went because his family thought an assessment would be a good thing.

They did not realise he would stay there.

Eden was upset at being away from home.

In the Unit he lived in a locked room by himself. There was no toilet. His food was passed through a hatch in the door.

He lashed out at staff. Then he was ‘Sectioned’, meaning he could not leave because the doctors said he was mentally ill.

He put on lots of weight - 16 stone!

Then Eden was sent to a psychiatric Unit even though he did not have mental health issues. This was better except that it was out in the country and miles away from his family who live in London. It took them 13 hours to get there and home again.

Eden loves swimming but the nearest pool was miles away. There were never enough staff to support Eden to go swimming.

He spent most of each day in his room or walking in the grounds.

At his first Review meeting Eden said ‘I don’t want to live here, I would give it one out of ten. I like looking after animals best. I want to live in London near my mum’.

The commissioner from his home area met with the family and said they would start planning.

But things got worse for Eden.



Eden can talk and say how he feels and what he thinks. But the Unit tried to stop Eden having a voice. Eden is on lots of drugs. Eden, not staff, told his mum that his medication had gone up. When he is on lots of drugs he does not talk much. His family think the drugs are used to keep him quiet.

The family are not allowed to phone Eden direct. He has to ask to phone them. The staff stopped Eden talking to his mum’s boyfriend because he was not family. Following this, Eden’s mum heard that Eden had hit out at 3 people in the unit. She worried that this could be used as a reason why Eden shouldn’t be let out.

When mum does speak the call is on loudspeaker. His speaking is slurred because of the drugs. He said ‘mum I can’t get the words out’ because his face is paralysed as a side effect of the drug. The drugs are also shutting his thinking down, which makes it hard for him to make choices and ask. The unit are using phrases like it is in his best interests, his choice etc. His mum is watching him sink into himself.

His mum is also concerned he is not getting enough to drink. He used to ask for a drink frequently but he doesn’t now. It is important he drinks enough water being on so much medication. His mum has raised concerns about this. Being on the drug shuts his thinking down and may mean he doesn’t ask for a drink.



Eden’s mum wants Eden to live near her in London. And Eden said he wanted to be ‘living in his own house near mum’. But his Local Authority placed Eden in Norfolk. They did not want to arrange the care package for Eden near home. Probably because London is so expensive to live in. In the meantime, Eden will shortly be entering his eighth year, away from his home and family.

*This is an edited version of Eden’s story on #7Daysofaction, a campaign to get people out of institutions in April 2016. The Open University thanks Eden and Eden’s mum for permission to use his story.*