Case Study 2024: Adam's story

Adam, 69, was born deaf and was later diagnosed with Usher syndrome, type 1. This led to his sight deteriorating in early adulthood and he now has a very small amount of tunnel vision in one eye only.

Growing up, Adam wasn't taught British Sign Language and relied on lip reading and basic gestures at home. His family were very protective of him and are described as not wanting to acknowledge Adam's deafness. His life at home is thought to have been highly routined, doing the same things every day in the same way. Adam appears to have had a life where decisions were often made for him.

Adam went to a specialist deaf school, but BSL was forbidden, so communication has always been difficult. Although he has since learned some BSL, his sight loss has hindered his learning and therefore, he is not a fluent user.

Adam' support worker said: "For most of his life Adam was told how to live his life, either by staff at school or his parents. This was done with the best of intentions, however it meant that Adam was not given the choices in many aspects of his life and now lacks the skills to make decisions."

Having lived with his parents into adulthood, Adam now lives alone in his own flat in a sheltered living complex. He has limited contact with his family and his brother, who he was very close to, died suddenly last year.

More recently, Adam's health has deteriorated and he has withdrawn from engaging with anyone. He spends much of the day sitting alone in a chair and sleeps in the same chair at night, choosing not to go to bed. He is extremely isolated and experiencing significant sensory deprivation. His behaviour is now causing concern – he appears to be hallucinating and is agitated and aggressive at times.

Adam's support worker feels that his deterioration has been exacerbated by the Covid lockdowns. The café that Adam liked to visit closed, and he saw less of his brother. "We came out of isolation and Adam hasn't." She said. Adam's physical health has also been impacted – he has been admitted to hospital with dehydration weighing 6 stone.

When Adam had a Social Care Assessment in 2024, he did not show any signs of engaging with or responding to the Assessor. He was completely disconnected.

Adam's support team had previously attempted to teach him 'hands-on' signing – a tactile form of sign language. But Adam didn't like people touching his hands and withdrew. Knowing that he has a limited knowledge of the English language, support staff have also tried to teach Adam braille, which he appeared to be enjoying, but later withdrew from.

Adam is now in a very difficult place, refusing to communicate even his most basic needs/ For example, pain from extremely red and sore feet. His increasing withdrawal from those around him leaves him at ever increasing risks from severe isolation and sensory deprivation. And when he doesn't use his communication skills, there is a risk that he will lose them.

Worryingly, Adam no longer sleeps in his bed. It is believed he stays up all night sitting in a chair in his lounge but no one has been able to find out from Adam why he does this.

Adam used to go out to the aquarium, café's, Deaf club and occasionally out on day trips but sadly, he has little interest in these activities now. His support worker said that, when they were out, he used to look around, taking an interest in his surroundings. Now he has his head down, uninterested. At home, he sits and does nothing.

It is unclear what Adam wants or why he is no longer engaging. Before he died, Adam's brother had said that Adam valued the opportunity to live independently, to have consistency in support workers and to have pride in his appearance. His current support worker agrees, saying that she feels his decline is related to being isolated and that Adam would want more human interaction.

The Social Care Assessor from Deafblind UK recommends that Adam remains living in his own home with improved communication and engagement with others, actively participating in daily living activities and in hobbies and activities within the community of his choosing. This is to be achieved via a period of assessment and reablement and an ongoing support package of a small team of Communicator Guides/Support Workers.

She recommends that Adam has an urgent referral to a Specialist Mental Health service for Deaf and Deafblind people. This is in addition to an assessment by an Optometrist with experience in deafblindness to have an up-to-date assessment of Adam's functional vision.

It is also advised that support staff keep a record of Adam's unusual behaviours to assess, the nature, type, frequency, possible triggers etc.

Adam is unable to initiate contact with anyone, which is safeguarding concern. Therefore, it is recommended that he is referred to a Technical Officer for Deaf and Deafblind people for an alerting device for the door to the flat and to call for help in an emergency.

Finally, it is suggested that Adam has a six-month period of ongoing assessment and reablement, led by skilled specialists and implemented by a small team of Communicator Guide/Support Staff. This programme will aim to develop Adam's communication skills, daily living skills and help him to re-engage in hobbies that Adam finds stimulating and enjoyable. It is also suggested that Adam has a one-month trial of a member of staff sleeping in his flat, to prompt and guide him into a

bedtime routine and sleeping in his bed. This to then be reviewed and a decision made if this needs to continue.