

How many people are prisoners in their own homes?

It is shocking to think that even today parents of people with learning difficulties find it easier to keep their children locked away at home. Working for the RNIB **Gill Levy** heard about several of these 'hidden people'. Here she writes about Albert whose story has a happy ending – but many were not so lucky.

Nothing could have prepared me for the tragic enquiries I received in my time at RNIB. Last week I was reminded about the desperate 'phone calls from staff concerning 'newly discovered people'. I had been chatting with an Asian friend who had met his first 'hidden child'. He had wrongly believed that only certain minority ethnic groups would be so ashamed of their disabled son or daughter that they would hide them away from the world.

People had 'phoned me about these 'hidden people' from a wide variety of backgrounds and classes. And I don't mean people with learning difficulties locked up in institutions. The enquiries were frighteningly similar – visually impaired people with severe learning difficulties confined to the parental home and not allowed out under any circumstances. Some people had been 'discovered' by services; others were 'found' when a carer died or became too frail.

Distressed and confused

The staff who contacted RNIB could not believe that parents would hide their children for so long. Callers were distressed and confused by their visits to the family home. They encountered elderly parents who clearly loved their adult sons and daughters and genuinely believed they were protecting them from harm.

It struck me there were two reasons given to staff by parents. Some mentioned that keeping their son or daughter 'indoors' stopped other people looking at them, calling them names or bullying them. Others told staff that taking their blind and disabled child out was 'so incredibly difficult and distressing' that the dreaded outings ceased.

"It was easier that way", they said. Staff were always angry that a person's rights had been so grossly infringed and their lives restricted. They always promised to tell me how these stories ended and usually did. Most did not have happy endings – because they

experienced sadness and loss and found it hard to adapt to a new life. But Albert's story was different.

Albert Green lived with his mother in the house where he was born 43 years ago, outside a rural hamlet. His brother, Robert, had long disagreed with his mother about Albert's care – but he phoned her each morning. When any of the few visitors came to the house Albert was promptly sent to his bedroom and when she went out. He was locked in whenever she went out. One day Mrs Green collapsed and died. Albert answered the telephone for the first time in his life and talked to his brother. Robert rang social services. Janie, a newly qualified social worker, 'phoned me. She had not met Albert and felt overwhelmed by the thought of assessing him and finding somewhere for a newly bereaved severely disabled blind man that no-one knew anything about.

Robert could provide basic information but felt he did not really know Albert. "He was just an extension of Mum in her eyes and he was never allowed an opinion on anything", Janie said.

Birth not registered

Robert explained that Albert had never been outside the family home. His birth was not registered, the midwife and his mother taking the view that babies with Down's Syndrome did not live long enough to make it 'worthwhile'. He had never been to school or mixed with people as his mother was convinced an infection would kill him. No doctor had ever seen him. If Albert became ill, Mrs Green would ask the GP for medicine, pretending it was she who needed it.

After spending the morning with Albert, Janie phoned me again. She was surprised at his good vocabulary although he had a marked lisp and was sometimes hard to understand. "He was clean and well dressed with impeccable old fashioned manners", she explained. She was horrified by his weight but felt 'truly charmed' by him. He had made his visitor welcome and apologised that he couldn't make tea. He was clearly shocked by his mother's death. She had warned him that this might happen and that he would have to go away. Through his tears he kept asking Janie 'Where? Where? Where?' His mother had told him that if he went out, he might 'get caught and locked up where no-one could visit him'.

Albert was placed with two retired nurses, recently approved as carers. I suggested they contact the rehabilitation office for the visually impaired (ROVI) urgently, who would explain how to help Albert.

Favourite soaps

Two weeks later, Janie rang. "Things are going well", she said. Robert had taken Albert to his mother's funeral and he had put flowers on her grave. He talked about her and his old home all the time for the first week but later the subject frequently changed to his favourite soaps.

About a month went by before I heard from Janie again. She was very excited. "We took everything gently, like you said. We really took on board that he is blind and that he'd need a lot of help to make sense of things. We were aware that he might be frightened and confused by such a mega change in his life. But Albert's a really sociable guy. He loves meeting new people and going to new places. He's trying to be more independent – I think he's making up for lost time". The carers took Albert to their GP who examined him closely and confirmed that Albert had a serious heart problem. He would have died young in those days if his mother hadn't cared for him so well.

An eye test showed that Albert was not blind but severely shortsighted. He quickly realised how much more he could see with his smart new glasses. Months later I was standing behind an exhibition stall at Learning Disability Today when a smiling woman peered at my name badge.

"Oh, you're Gill. I'm Leanne. Delighted to meet you. Hold on a moment and I'll find Albert". She vanished for ten minutes, re-appearing with a small, podgy red-haired man, who was grinning from ear to ear. "Tell Gill about yourself, Albert", she said. It was as if Albert had prepared a speech and practised delivering it! "I lived with my Mum all my life. I loved her but she wouldn't let me go out and wanted to keep me safe.

She's dead now. I miss her a lot and Joe and Leanne (his carers) keep me safe now. The doctor has given them lots of advice about how I can go out and not get ill".

Assertive

A year later Leanne again came to my exhibition stand to tell me that Albert would soon move into a shared flat. She was delighted at how he had coped with his new life, learned new skills and become assertive. "We've got an extroverted personality shining through. I'm so very proud of him".

Gill Levy provided an information service on sight problems and learning difficulties for 21 years.