in their families. In contrast, a few took it in their stride and were keen to get other family members tested.

All newborns in England are now screened for SCD, regardless of ethnic origin. Early diagnosis and prompt management of SCD can prevent deaths of young children from life-threatening complications such as pneumococcal infections.

I am sure the social workers had done their best, and nurses could just as easily have been caught up in this common dilemma. But the right action here needed people who could see and respond to the whole picture. It required the intelligence to know not only what the rules are, but how to break them and for the right reasons. Breaking the rules is something that we as carers are not often encouraged to do, especially in a system where new gods, targets, costs, regulations, demand obedience.

Perhaps we need modules in nursing education explicitly on ‘how to break the rules’ and ‘how to acquire wisdom’. People like Richard and Beryll need wise advocates who, no matter what the regulations say, mould the system to the patient and not vice versa. Anyone who has been in such situations will know what rough terrain it can be, but wise nurses know how to traverse its pitfalls and obstructions safely – for those they serve and themselves.

Integrated intelligence can produce wise humans in the caring professions. And wisdom is power, the ‘quiet power’ that was so beautifully illuminated in last year’s Nursing the Future campaign in Nursing Standard.

Inseparable

As I write, Richard and Beryll Driscoll are in the news. Both aged 89, they had been inseparable for 65 years until social services refused to house them in the same care home. Their needs were different, so, according to the rules, they could not be placed together. After protests from their family and the media, the decision was changed.

Stephen Wright is professor at the Faculty of Health and Social Care, St Martin’s College, Carlisle, and chair of the Sacred Space Foundation

Reference


There is a valuable lesson from this experience that will be useful for planned screening programmes, such as for cystic fibrosis (CF). This condition is seen mainly in white communities, but other ethnic groups can also inherit it. The CF Trust recognises that the condition is also found within BME groups.

The organisation has produced audio tapes in Urdu and Gujarati aimed at South Asian parents and adolescents affected by CF. In the near future, newborn screening for CF will be rolled out across England and for all babies, as with SCD. I wonder, would it be helpful to produce another video?

Elizabeth Anionwu is head of the Mary Seacole Centre for Nursing Practice, Thames Valley University

All babies are now tested for sickle cell disorders, regardless of ethnicity

The science bit

SUBSTITUTE BLOOD FACTORIES EXPLORED

Research is under way to develop a safe, cheap and effective blood substitute for transfusions. The Euro Blood Substitutes project, sponsored by the European Union, aims to create practical cell factories producing a genetically modified haemoglobin, the protein that carries oxygen around the body.

Researchers want to use Aspergillus niger fungus and Escherichia coli bacteria to create supercharged haem proteins, helping create reliable supplies of alternative blood products.

Haemoglobin can be sourced from spare donor and cow blood, but fungi and bacteria could generate it on an industrial scale. Project co-ordinator Kenneth Lowe from Nottingham University explained: ‘We are using genomics to modify haemoglobin as well as examining ways to attach it to large molecules so that it stays in the body longer during transfusions.

‘We are aiming to find the optimum molecules for oxygen-binding and transport, as well as the best culture conditions for mass producing it for the future.’

The project cites three key advantages to blood substitutes: unlike red blood cells, a blood substitute could be sterilised; mismatching of blood types with donated blood through human error would be minimised; and a blood substitute could be stored for a long time allowing transport to developing countries, battlefields, or natural disasters.

Keith Nuthall and Monica Dobie are freelance journalists

For further information go to www.eurobloodsubstitutes.com