

‘I need help with things I can’t do myself, like cooking or driving, but I employ personal assistants to do that, not carers’

# Helping others to make sense of disability



**By Jane Bakowski**

SIMON Wilson doesn't do walking on eggshells.

For while others may tiptoe around the complex issues which surround living with a disability like cerebral palsy, the 31-year-old social psychology graduate, who lives in Sherwood Way, Tunbridge Wells, is resolutely upfront about it. In fact, through workshops and mentoring sessions run by his company, SimonsAble, he aims to stand much of the current thinking on disability on its head.

For a start, there's the word carer.

"I need help with things I can't do myself, but I employ personal assistants to do that," said Simon, who has limited control over his body and a speech impairment. They drive me to places, cook for my directions or take me to nightclubs, but it's my family and friends who care for me.

It is this directness that shapes not only his own life, but also his work with schools, companies and other organisations to raise dis-

ability awareness and provide training in breaking through what can seem an impenetrable barrier.

He said: "I want to communicate openly with people, so I don't mind what they ask me because I want them to understand. It can be frustrating, of course.

### Communicating

"I am a person who loves hugs, but I can't just put my arms around someone; in the same way, I have had to find alternative methods of communicating without speech using body language, a computer that I operate by touching a mousepad with my cheek, or a letterboard, where I spell out words by focussing on the individual letters.

But with a mind dancing with ideas, an iron will and the kind of sharp intelligence which has enabled him to make his own way through the minefield of both special and mainstream schools, college and university, he has a rare gift for connecting with people. I'm never shocked by the

questions they ask, even if they are quite personal," said Simon, who recently ran a workshop at Tunbridge Wells High School.

"I find children come out of their shells much easier when they are interested in what is being discussed, and if they want to talk about sex or relationships, that's fine."

One of the tools he employs is the setting of tasks. By learning to speak to each other via a letterboard or using questions which only require yes or no answers – recognisable by clearly understood signals – his audience can begin to understand how he operates. "I would also like to do more work with families so that all those who have a child with a disability get the right help," said Simon, whose relationship with his parents and younger brother, Matt, has always been close. "When we were little, Matt used to wrestle my arms and legs or whizz me up and down the aisles in the

supermarket. My mum would hear me laughing with de-light." Simon is now working on a book about his life because, he says, "it is a chance to show how I perceive things. Not being able to speak means I have to be economical with words, so this means I can explain how I really felt about things when I was young. I think my family and friends would love to know that, and it should be interesting for other people, too."

### Students

For whether he is recruiting personal assistants, talking to groups of students or staff or banging off one of his frequent letters to the Government – he recently picked up a peer in the House of Lords for referring impersonally to handicapped House of Lords for referring impersonally to the handicapped – he is not only in charge of his own life, he is also gently guiding those around him into a real understanding of what disability means.

He said: "I never give up. When I was a young boy I had a tricycle I rode stupidly fast, especially round corners, and often I tipped it over. I don't like half doing something, and if I'm capable of doing it myself I'll kindly decline any help offered."

"That's just me.

SimonsAble offers workshops for both disabled and non-disabled people, plus individual mentoring and consultancy services. Call 01892 516787 or visit [www.SimonsAble.uwclub.net](http://www.SimonsAble.uwclub.net)



**HOLIDAY FUN:** Cornered by Marilyn Monroe on a boyhood trip to Florida



**Training:** SimonsAble offers a range of disability training workshops and seminars