

Supporting People with a Learning Disability and Autistic People in Health and Social Care

Janet Finlayson

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Foreword

Our daughter, Laura was born with Down syndrome. She suffered severe brain damage following surgery at one year old. Laura has complex needs, but she has the nicest personality of anyone I know. We are so lucky to have her as a daughter. Every day she teaches us about what matters in life, and no matter what she is going through, she always manages a smile. Laura has two main passions in life: going out for trips in her car and 'the Singing Kettle' (a Scottish music group).

We converted an area of our house into a self-contained flat for Laura. We call it 'Laura's pad', to which she has her own front door. Laura has a personal support package and budget, which means she has her own paid support team, who provide her with support 24 hours a day, 7 days a week. This arrangement has been very successful because the support is always focused on what is best for Laura. Laura enjoys being more independent, and for us it means being her mum and dad instead of her carers. Laura is so independent now, that sometimes when I knock on the door to see how she is getting on with her support worker, she says 'bye' and shoos me out of her flat for trying to interfere or fuss over her. This makes me laugh and makes me really happy. Support that is designed around the person, according to their individual needs, works best for everyone, and should

be realised for more people, as it has been for Laura and our family.

Laura has had a few negative hospital experiences, including two separate occasions of being admitted with a suspected chest infection and nearly losing her life because ward staff didn't listen to or respect us as her parents and experts who could help. These instances involved not being allowed to stay with Laura during routine procedures, medication she had been taking for over 30 years being withdrawn suddenly, not being given pain relief when it was obvious to us that she was in pain and not being allowed to follow the postural care management that we do with Laura at home. Postural care management is very important for Laura's respiratory health, as it is for other people with postural issues.

Based on Laura's and our family's experiences, I often give talks to health and social care staff at training events, seminars and conferences, so lessons can be learned from these experiences. I jumped at the chance to be part of this, to make a positive difference to the healthcare experiences of people with a learning disability and autistic people through training. I am happy to do this. But it isn't always easy for me to talk about these deeply personal matters, and at times I feel emotionally 'raw'.

This book demonstrates positive values and attitudes, and it shows throughout a respect for every individual. It's not often I come across the right values and attitudes when I am reading books about

people with a learning disability and autistic people, especially if the person's disability is severe or complex. However, this book does just that while also covering so many important issues within a manageable length. The inclusion of expert voices also helps the reader to visualise the impact of these issues on real people's lives.

Marion Mcardle
Expert voice

Acknowledgements

With thanks to the expert voices for their valuable contributions. Thanks also to Brad English and Tracy Radford at OneConversation in Nottingham for their support. The expert voices are: Zahra Al Jardani, Vicky Deakin, Sam Gwynn, Shimara Hyman, Brett Kinsley, Marion Mcardle, Lizzie Quayle, Kriss Steer and Ethan Wright.

About the author

Janet Finlayson is a Registered Mental Health Nurse and Senior Research Fellow at Glasgow Caledonian University. Her research is focused on improving the health and wellbeing of people with a learning disability and autistic people. She has over thirty years' experience working with people with a learning disability, autistic people and their supporters. She also teaches research methods to postgraduate students.

People with a learning disability and autistic people

People with a learning disability and autistic people are different groups. ‘People with a learning disability and autism’ only refers to people with both conditions. It is respectful to refer to someone as a person with a learning disability, as you are putting the person first before their disability. However, some people, including many of the expert voices who contributed to this book, refer to themselves as being a learning-disabled person. For autistic people, some prefer the term ‘people with autism’, while others prefer the term ‘autistic people’. The latter perceive their autism as being natural to who they are as a person; just as important to their identity as their religion, ethnicity or sexual orientation.¹ We will be referring to people with a learning disability and autistic people throughout this book, but want to stress the importance of being respectful and using the term that is preferable to the person/s to whom you are referring.

A diagnosis of ‘learning disability’ or ‘autism’ leads to better understanding of an individual’s needs and helps them access appropriate health, educational and social services. Of course, a label such as ‘learning disability’ or ‘autism’ only describes part