

Background to Insiders' Guide



The original edition of Insiders' Guide was published in 2006. Based on a pilot funded by The Parenting Fund and evaluated independently by the University of Brighton, most of the materials were developed from the experiences shared by parent carers and practitioners.

Co-production with parent carers helped define course themes and content. They reported the need for many more courses and modules than we were able to supply, hence Insiders' Guide was designed with growth in mind. Invaluable contributions were made by the team of 11 parent-practitioner co-facilitators who tested the materials as they delivered the first course to five different parent groups in 2005-06. Recent research in Calderdale and East Sussex has since evidenced that this course substantially contributes to a cultural shift of solution-focused partnership working with families.

Insiders' Guide starts from the parent or 'insider' perspective. Surprisingly, very few courses speak to the unique characteristics of bringing up a child with special needs, even fewer involve parent carers in their design and delivery and rarely do courses model and promote finding solutions together.

Insiders' Guide focuses on building resilience and what can help when life is particularly tough. Wide ranging research has consistently shown that families of children with special needs are more likely than others to experience poverty, relationship breakdown, general health and mental health problems, unsuitable housing and problems associated with employment. Resilience is the ability to withstand and recover from stressful life challenges, strengthened and more resourceful.

Many parents face a steep learning curve and are met with obstacles as they try to gather information and knowledge about their child's disability or needs and the support likely to be available for them. Many are managing varying degrees of loss or disappointment as their children reach regular developmental milestones differently to other children. Celebrating ordinary experiences and joy can get lost.

Insiders' Guide is aligned with the social model of disability, where the child is valued, their strengths and needs defined, support and resources made available, diversity welcomed, training for parents and practitioners offered and relationships are crucial. It rejects the medical model of disability where the child is seen as faulty and their impairment becomes the focus of attention while ordinary needs are put on the back burner with specialist assessments and services take priority.

Parents guided the language chosen so that we use the term 'special needs' to include a diverse range of children with disabilities, special educational needs, complex health or behaviour issues and the term 'parent carer' to acknowledge additional caring tasks and anyone in a parenting role such as foster or adoptive parents, grandparents and carers too.

Insiders' Guide was designed by Kim Aumann and Carrie Britton, founding members of Amaze, the Brighton based parent led charity. Kim was the organisation's first Director and is now Co-Director of Boingboing, a community interest company promoting resilience research and practice. She has worked with parents for the past 20 years and is a Visiting Research Fellow at the University of Brighton. Carrie is a parent whose own experience informed her doctoral research on the challenges families manage when bringing up children with complex health needs. She works as an independent advisor and trainer to improve the design, delivery and standards of services for families of children additional needs.

Insiders' Guide continues to be developed in collaboration with Amaze and Professor Angie Hart at the University of Brighton.

Download additional information sheets about Insiders' Guide from: www.amazebrighton.org.uk OR www.boingboing.org.uk

- About Insiders' Guide
- Insiders' Guide Course Costs
- Tried and Tested – Evaluations of Insiders' Guide
- Facilitating Together – the Art of Co-delivering Insiders' Guide