Call for Research Participants

The death of a child, whatever their age, is devastating. The needs of people with learning disabilities and/or autism with additional complex needs, and their families, are often overlooked. Families often have to fight hard to get the support they need. People with learning disabilities and/or autism with additional complex needs sometimes (but not always) also have additional health complications. Sometimes this results in difficulty accessing health or support services, which can sometimes result in them dying much younger than those without learning disabilities and/or autism. Little is known about parents’ experiences after the death of their child, or the support available to them at such a difficult time.

This study explores Parents’ experiences after the death of their child with a learning disability and/or autism with additional complex needs, such as additional physical, visual or hearing impairments, mental health issues, additional health needs such as epilepsy or behaviour that challenges. We are particularly interested in the support people have received and their experiences of other people’s attitudes towards the death of their loved one. We would like to talk to people who are in this situation.

We are aware that this is an extremely distressing experience and you may not want to discuss this with anyone, but we would appreciate your help in finding out more about the experiences of bereaved families. A minimum of a year needs to have passed between being bereaved and taking part.

Whether your loved one was child or adult when they died, whether their death was expected, or unexpected, no matter how long ago they died, we would like to talk to you. If you are interested in sharing your experiences or you would like to find out more about the study, please contact Beckie Lisney at the Tizard Centre (e-mail: rcl7@kent.ac.uk phone: 01227 827771). If you know anyone who might be interested in this research, please forward this information to them. Thank you!