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Parents' views and experiences of talking about autism with their children

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When a child is diagnosed with autism, clinical professionals need to relay information about the diagnosis to the child's parents: explaining what autism means and the impact it may have on their child. Whilst there is a body of research on how clinical professionals disclose an autism diagnosis to parents of autistic children, relatively less is known about how parents subsequently relay this information to their autistic children (if at all) or how parents talk about autism with their families more broadly. Using an online survey, we gathered the views and experiences of 558 parents of autistic children, all based in the UK. We found that most parents (68%) had told their autistic children about their diagnosis. Although few parents had received advice or support about this, most thought that these discussions had gone well and they felt confident in talking about autism with their children. Those that had not told their children about their diagnosis had a range of reasons for not doing so (e.g., because their children were too young to understand the diagnosis); yet many intended on telling their children about their autism diagnosis in the future and felt confident in doing so. Three key messages were conveyed by the parents who took part in this survey: (1) The importance of being open about the diagnosis (introducing the concept of autism gradually, in a way that is enlightening and empowering for the children); (2) The need to tailor discussions about autism to the child's specific needs (paying particular attention to celebrating the positives); and (3) That challenges may arise when talking about autism (specifically, that telling children about their diagnosis could, in some cases, have a negative effect, so professional support may be helpful).