

Do Not Conceal Your Child's Autism Diagnosis

By

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## **Abstract**

This essay explores the ethical implications of parents concealing their children's autism spectrum disorder (ASD) diagnosis. It argues that non-disclosure is unethical as it limits self-advocacy, causes harm, and damages trust. Self-advocacy for children with ASD is important in obtaining opportunities to ensure an open future. In addition, the idea that non-disclosure protects children from social stigma is challenged, as concealed stigma can cause distress. Finally, non-disclosure causes the breakdown of trust between patients, family, and healthcare providers, impeding management. There is a need for transparency about ASD diagnoses, with healthcare professionals providing support to parents in navigating these conversations.

## **Introduction**

Children's autism spectrum disorder (ASD) diagnoses are often delivered solely to parents, leaving them to confront the ethical dilemma of whether they should inform their children about it<sup>1</sup>. Some hide the diagnosis from their child to protect them from harm. For example, parents may fear that their child would experience social stigma or feel ashamed and limit themselves from reaching their full potential<sup>1 2</sup>. Other reasons to non-disclosure include parents' own shame and denial, the belief that their child's autism is not a "big enough" issue and that their child will not understand the diagnosis<sup>2</sup>. This essay, using a case from the United States, argues that it is unethical for parents to conceal their children's ASD diagnosis from them as it limits children from self-advocacy, causes more harm, and damages the trust between patients and their family or doctors. There is a need to provide professional guidance and clinical support for parents to make conversations easier with their children.

## **Case Description**<sup>3</sup>

At fourteen, Reid Knight discovered through Google that the medication he had been taking since a toddler was a treatment for autism. For twelve years, he was given ten to twenty pills a day, while being on therapies such as Applied Behavioral Analysis without knowing why. He struggled to fit in at school and never understood why he could not do things that came easily for his peers. His parents only informed him of his ASD diagnosis when they discovered his online search history. Their reason for not disclosing to Reid earlier was because they claimed that the medication 'cured' him of his autism and so he did not need to know. As an adult, Reid struggles to cope with the trauma from not knowing about his diagnosis.

## **Argument 1: Importance of Self-advocacy**

Joel Feinberg coined the concept of a child's right to an open future, suggesting that children will one day become capable of autonomous decision-making, so their future opportunities should not be limited<sup>4</sup>. ASD is an incurable neurodevelopmental disorder. Current therapies and medications are available, but only to prevent worse outcomes<sup>5</sup>.

To truly protect the open future of children with ASD, they should be informed of their diagnosis earlier in life, empowering them to advocate for themselves. According to a study published in the journal *Autism*, university students who learned about their ASD diagnosis at a young age reported greater well-being and quality-of-life relative to others who did not<sup>6</sup>.

Learning about one's diagnosis can help them make sense of their experiences to build self-understanding and self-compassion. Those that learn about their ASD as children may regard the diagnosis as a positive or neutral aspect of themselves or consider themselves a valuable form of human diversity<sup>6 7</sup>. Having this perspective instilled early on allows children with ASD to speak out for themselves and look for relevant support when needed. This could come in the form of finding allies with autism, mental health counselling and reaching out for physical assistance from institutions like schools. Since much more effort has historically been dedicated to supporting children with autism than adults, adult autism diagnoses rarely provide clear pathways to formal support, explaining the reduced well-being and quality-of-life among those who learn about their ASD later in life<sup>8</sup>.

Had Reid known about his formal ASD diagnosis earlier, he could have strove for relevant individualised accommodations from his school to aid participation in activities he originally thought were too hard. He could have also sought help from counsellors to address

his feeling of 'being different'. Self-advocacy leads to better opportunities and environments to realise their potential, increasing chances of disseminating into society and thus promising an open future.

However, one could argue that informing children of their diagnosis might 'prevent a child from being able to be a kid'<sup>4</sup>. Disclosing to Reid that he has ASD could potentially impose unnecessary burden by making him more aware of his differences from his peers and strip away his innocent and free childhood. There may also be a worry that children cannot fully comprehend the diagnosis, hence not knowing how to better advocate for themselves.

However, these concerns do not outweigh the proven benefits of self-advocacy and justify non-disclosure. Rather, they highlight the need to inform their children of their ASD diagnosis as early as possible at an age- and developmentally-appropriate fashion.

### **Argument 2: More Harm Than Good**

An argument for non-disclosure is to protect children from social stigmatisation. Parents worry that their child with ASD would reveal the diagnosis to other children who would then isolate or ridicule the child based on it<sup>9</sup>. Since children with ASD do not have very visible physical features, parents may perceive this as a positive<sup>10</sup>. If no one can see that a child has a problem, the child would not be stigmatised, making it unnecessary to inform children of their diagnosis. However, this may not be true. Concealed stigma is defined as 'a stigmatised identity that is not immediately knowable in a social interaction'<sup>11</sup>. When a child with ASD acts 'differently' from peers but has no physical markers to act as an explanation, they may in fact be judged and isolated more harshly due to a lack of pity. Even though 'pity' carries negative connotations, it has elements of compassion and empathy. It has been argued that stigmatisation

decreases with visibility: the more physically visible a condition is, the less stigmatizing it is due to an increase in pity<sup>10</sup>, which could lead to protective effects and less judgement on the child.

Moreover, children living with ASD are often aware of their differences. This may stem from difficulties in social interactions or, like in Reid's case, seeing doctors and receiving treatments without being told why. In these situations, children and their parents enter a state of 'mutual pretense', in which both parties are aware of the child's ASD (albeit to different extents), but refuse to acknowledge it openly<sup>4</sup>. Hence, the argument of non-disclosure to protect children from being ashamed about their ASD diagnosis is based on the false assumption that children are ignorant to their condition. By withholding ASD diagnoses from children, they may go through a process of 'self-diagnosis' and arrive at the wrong conclusion about their perceived differences<sup>12</sup>, in turn causing unnecessary stress.

In addition, people who are aware of their differences caused by ASD may try to camouflage their traits to fit in. Unfortunately, research has shown that such practices of internalising and concealing stigma can be psychologically damaging, causing anxiety, low self-esteem and self-acceptance problems among other issues<sup>13</sup>.

### **Argument 3: Problem of Trust**

Healthcare is fundamentally built on trust. In paediatrics, the concept of trust exists beyond the professional physician-patient relationship to the trilateral relationship between paediatric patients, parents and physicians<sup>4</sup>. As demonstrated by Reid, inevitably, children will one day find out that they have ASD, be it through the internet or a service provider accidentally mentioning it. Children will realise that their parents and healthcare providers 'hid' something

important regarding their identity. In cases where parents tell other family members or friends about the diagnosis, the child may feel even more devastated knowing that ‘everyone else’ knows more about their own body and identity than they do. The trust in the healthcare system and family, once destroyed, becomes difficult to repair. Patients with ASD may feel lost, not knowing who to trust and seek help from.

Providing children with the opportunity to know of their ASD diagnosis and participate in healthcare decision-making may improve the trilateral relationship by building their trust in both parents and healthcare providers<sup>14</sup>. In Reid’s case, for example, instead of giving him medications or bringing him to therapy without any explanation, he could have been invited to provide informed assent. This shows respect to the patient and reduces his feelings of powerlessness knowing that he is involved in his own care. Since ASD is a lifelong condition, people with the condition greatly benefit from having trustful relationships with family or healthcare professionals in the field. Showing respect and allowing some control over the ASD diagnosis at a young age sets a good foundation for the future where the person would feel more comfortable discussing it and seeking assistance.

## **Conclusion**

When faced with the dilemma of informing a child of their ASD diagnosis, parents should not hide the information from them due to the child’s right to an open future, potential harms done to the child and the breakdown of trust. However, navigating through the dilemma of disclosing ASD diagnosis to children is hard, especially when it is unclear when and how to deliver the information is best for the child. In addition to providing therapies and check-ups for children, healthcare professionals should also encourage transparency within the parent-child relationship. Healthcare professionals should engage actively in counselling sessions for

parents to ease off their stress. In addition, doctors could offer tailored links to relevant services such as support groups or social workers to help parents better understand their children's needs and learn about good practices in disclosure conversations.



## References

1. Almog N, Kassel O, Levy N, et al. Mapping the Dilemmas Parents Face with Disclosing Autism Diagnosis to their Child. *Journal of Autism and Developmental Disorders* 2023;53(10):4060-75. doi: 10.1007/s10803-022-05711-y [published Online First: 20220811]
2. Smith IC, Edelstein JA, Cox BE, et al. Parental Disclosure of ASD Diagnosis to the Child: A Systematic Review. *Evidence-Based Practice in Child and Adolescent Mental Health* 2018;3(2):98-105. doi: 10.1080/23794925.2018.1435319
3. Knight R. Parents: Don't Hide Your Children's Autism Diagnosis From Them. *Thinking Person's Guide to Autism*, 2017.
4. Marron JM, Kennedy KO. Telling the Child: Ethics of the Involvement of Minors in Health Care Decision-Making and in Considering Parental Requests to Withhold Information from Their Child. *The International Library of Bioethics* 2022:127-41. doi: 10.1007/978-3-030-86182-7\_8
5. Bölte S. Is autism curable? *Developmental Medicine & Child Neurology* 2014;56(10):927-31. doi: 10.1111/DMCN.12495
6. Oredipe T, Kofner B, Riccio A, et al. Does learning you are autistic at a younger age lead to better adult outcomes? A participatory exploration of the perspectives of autistic university students. *Autism* 2022;27(1):200-12. doi: 10.1177/13623613221086700
7. Mogensen L, Mason J. The meaning of a label for teenagers negotiating identity: Experiences with autism spectrum disorder. *Children, Health and Well-being: Policy Debates and Lived Experience* 2015:83-97. doi: 10.1002/9781119069522.CH7
8. Huang Y, Arnold SRC, Foley KR, et al. Diagnosis of autism in adulthood: A scoping review. *Autism* 2020;24(6):1311-27. doi: 10.1177/1362361320903128

9. Crane L, Jones L, Prosser R, et al. Parents' views and experiences of talking about autism with their children. *Autism* 2019;23(8):1969-81. doi: 10.1177/1362361319836257
10. Wnoroski AK. Uncovering the Stigma in Parents of Children with Autism, 2008.
11. Quinn DM, Earnshaw VA. Concealable Stigmatized Identities and Psychological Well-Being. *Social and Personality Psychology Compass* 2013;7(1):40-51. doi: 10.1111/SPC3.12005
12. Wheeler M. Getting Started: Introducing Your Child to His or Her Diagnosis of Autism: Learn About Autism: Indiana Resource Center for Autism: Indiana University Bloomington, 2020.
13. Botha M, Frost DM. Extending the Minority Stress Model to Understand Mental Health Problems Experienced by the Autistic Population. *Society and Mental Health* 2018;10(1):20-34. doi: 10.1177/2156869318804297
14. de Zulueta P. Choosing for and with children: consent, assent and working with children in the primary care setting. *London Journal of Primary Care* 2010;3(1):12-12. doi: 10.1080/17571472.2010.11493290