

## CASE 2: “Debarking” an Autistic Boy

The Hanegraafs were struggling to treat their autistic son’s vocal tics when they finally found a doctor who could help them. Kade was fourteen years old at the time and his tics were severe. He screamed upwards of 2000 times per day at a volume of 90 dB, about the same level as a motorcycle’s engine, and he had been doing so for over three years. The tics were taking their toll on the boy, his parents, and his twin brother (also autistic) who is sensitive to noise. The doctor and the boy’s parents decided the boy would undergo thyroplasty, a surgical operation that would soften the boy’s voice. The procedure has been likened to the devocalization of pets, especially dogs, sometimes called, “debarking.”

Two years after the surgery, Kade’s doctor, Dr. Dailey, published a medical report on the case and it began receiving media attention. Autism advocates, many of them adults with autism, were dismayed and disgusted by news of the procedure. Advocate Lydia Brown wrote, “There are other ways to address the issue than forced surgery...The surgery was performed because Kade was an inconvenience to his parents...This is torture.”

Ari Ne’eman, co-founder of the Autistic Self-Advocacy Network, was also staunchly opposed to the procedure and made this public statement on behalf of the network:

Autistic people and others with communication related disabilities often use what’s termed as ‘problem behavior’ as a way of communicating distress, anger, fear, anxiety or other important emotions that may not be easily communicated for someone without standard speech. There is a long history of family members and providers viewing these behaviors as strictly a medical phenomenon and not recognizing they’re important for communication. To violate a person’s bodily autonomy and damage their ability to communicate to serve the convenience of the caregiver is nothing short of horrific. We view this as similar to the Ashley X case or the long history of involuntary sterilization, teeth removal and other inappropriate and unethical medical procedures conducted against people with developmental disabilities.

Steve Silberman, a writer on autism, also worried that this was another example of a historical inability to cope with the atypical behavior that sometimes accompanies disabilities. “If your kid had a problem with ‘wandering,’ would you surgically hobble them?” Silberman asked, adding that “treating autistic people like dogs that need to be debarked is grotesquely inhumane.”

Dr. Dailey’s report claimed that six months after the operation Kade’s tics had reduced in frequency by ninety percent and in intensity by fifty percent. The doctor claimed Kade was showing signs of improvement in his social interactions, his educational development, and his nutritional health. Dailey spoke on behalf of the Hanegraaf’s claiming that it was not only the boy’s parents and brother who were tormented by his screams, but Kade himself suffered. He

couldn't go to school, develop friendships, or maintain a supportive system of caregivers because of his outbursts. The Hanegraafs claimed Kade couldn't even eat a full meal without screaming.

Kade's mother claims the operation was a miracle and that it would have been unethical to refrain from the surgery. "When you see it trickle down to his brother, this was a life sentence," she said, "I didn't see my son smile for three and a half years. Now, he has a whole new life inside him."

Questions:

1. If the surgery on Kade was done for the convenience or benefit of Kade's parents and his brother, and not solely to benefit Kade himself, does that make the procedure ethically wrong?
2. Some medical procedures requested by parents on behalf of their children are seemingly not morally problematic. How should we distinguish those procedures that are morally problematic from those that are not? According to your criteria, is Kade's thyroplasty morally problematic?
3. Evaluate the decision made by the Hanegraafs and Dr. Dailey. Was their decision and the reasoning that led to it ethical?

*Published by the official National Undergraduate Bioethics Bowl 2014 as part of the National Undergraduate Bioethics Conference 2014:  
"MORALS AND MEDICINE: THE ETHICS OF BECOMING A HEALTH CARE PROFESSIONAL"*

*Hosted by Loyola University Chicago  
Chicago, IL  
April 4-6, 2014*