

Robin's Story

To be used with "Autism, Through a Social Lens." By Stephen Poulson. *Contexts*. Spring 2009.

Purpose:

The purpose of this case study is to provide you with an opportunity to examine how social inequality manifests itself in the diagnosis and treatment of autism.

Directions:

Read the following case study and answer the questions. Be prepared to talk about your answers in small groups.

Robin is the son of Kathleen, a Filipino immigrant, and Tom, an immigrant from Jordan. Since Robin was three years old, his mother Kathleen had been aware of his difficulties. He was not talking, making eye contact or showing interest in other children. However, many of Tom's Jordanian family members told her, "He's fine. Boys develop slower than girls." Kathleen and her Filipino family knew something was wrong, but the word for autism doesn't even exist in either of the two cultures. Despite several visits to professionals to express her concerns, diagnosis of autism was not suggested as an explanation of Robin's difficulties (perhaps due to Kathleen's poor English).

During Robin's time in Kindergarten, Kathleen was frequently called in by teachers who complained about his anti-social behavior. The teachers said that he needed to be taught appropriate social skills, but Kathleen already devoted hours teaching Robin how to share and to recognize the feelings of others. All of these efforts failed, though. At primary school, reports from teachers continued to be negative. He was described as inattentive, lazy, defiant and insolent.

Finally, when Robin was nine, a psychiatrist diagnosed him as autistic. Kathleen and Tom were relieved at first as the blame was lifted from both their son and themselves. They could now start to make sense of Robin's problems and devise solutions. However, the diagnosis did not solve all of the problems coming from Tom's family. Their culture did not recognize diseases like autism, and special education was highly stigmatized.

Pragmatically, Kathleen and Tom faced an even bigger challenge. According to the psychiatrist, Robin would need at least 25 hours of direct contact per week with a trained therapist for a minimum of two years. However, autism is not covered by most health insurance providers; and given the high costs of the intervention programs, many schools do not provide therapy for autistic children. In fact, the school where Robin studied simply refused to identify Robin as autistic because officials regarded the cost of providing services as too expensive. As a result, the family had to move to another school district that had established autism programs. However, tuition that included his 25-hour-per-week therapy cost \$88,000 per academic year, far beyond what the family could afford. Luckily, Filipinos have a culture of sacrificing individual desires for the benefit of the family. Therefore, Kathleen and Tom have received much financial support from Kathleen's extended family. Nevertheless, Kathleen finally made a tough decision in order to better care for Robin--quit her job.

Questions:

1. Robin was diagnosed with autism relatively late and thus missed the most effective early interventions. What contributed to this late diagnosis?
2. How do cultural traditions, values and beliefs affect peoples' attitudes toward autism? Would there be any difference if this happened in your family?
3. To some extent, Robin is lucky because he can afford the cost for the therapy. According to a Harvard School of Public Health study published in 2007, it typically costs \$3.2 million to raise an autistic child into adulthood, compared with \$290,000 to raise a neurotypical child. How would this affect people's access to treatment, and what should our society do to address this issue?
4. In this story, who is responsible for the task of taking care of Robin? If you were Kathleen or Tom, would you make the same decision? Why or why not?