

## Should Kirsten Johnson be allowed to have kids?

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Vera Howse thinks her 26-year-old niece Kirsten Johnson wouldn't be a good mother, so she's asked the Cook County Probate Court for authorization to sterilize her niece against her will. Johnson is cognitively impaired, and her aunt is her legal guardian.

This case has broad significance because Illinois, unlike other states, hasn't established when a court should grant a guardian authority to have a ward permanently sterilized.

Most cases like this are resolved in the doctor's office. Physicians at one Chicago hospital system estimate that it receives one to three guardian requests to sterilize their wards per month, usually from parents of disabled adolescents. After counseling, most eventually opt instead for long-term reversible birth control.

But in this case Howse continued to insist that her niece be sterilized permanently, and her internist and psychiatrist did not object. Johnson countered by contacting Equip for Equality, a disability rights organization that represented her in court. Johnson, who lives with her aunt in south suburban Matteson, is sexually active. She has always used birth control (her aunt currently helps her use the patch), but says if she were to marry a man who could help her parent someday, she would like to have a child.

Historically speaking, Johnson's situation isn't unique. State programs forced up to 70,000 disabled and poor Americans to be sterilized between the early 1900s and the 1970s. These programs, now ended, were driven by a belief that social eugenics would both "improve the gene pool" and save the taxpayers money by reducing the number of children born to parents who couldn't support them.

The courts were no help. In Virginia, for example, the Lynchburg Colony for the Epileptic and Feeble Minded, which sterilized 8,300 people from 1927 to 1972, was a model of empty due process. The disabled and poor teens forcibly brought to the institution were given a perfunctory hearing, after which a judge would always find it was in the "best interests" of the patient and society that the ward not reproduce. In 1927 the Supreme Court upheld this Virginia statute in the case of *Buck v. Bell*.

Six years later, the Nazi regime in Germany modeled its new eugenic program on U.S. sterilization statutes. They began with the sterilization of disabled individuals in 1933, later executing thousands of persons with disabilities and millions from other "unfit" populations.

### Whose 'best interest'?

But things are different now, right? States have formally apologized for their eugenics programs, the Americans with Disabilities Act ushered in a new era of accommodation and respect, and the disabled person's right to medical self-determination is implemented by his or her guardian, who is usually a family member concerned with the disabled person's "best interests." At least that's the standard Illinois law tells guardians to use.

The problem is that childbearing is one decision in which what's best for the ward and what's best for the guardian might conflict. While some cognitively impaired people might enjoy parenthood, their guardians may fear a new baby will become the guardian's responsibility. Or, in the case of congenital disability, guardians may fear the ward will "pass on their genes" and bear another disabled family member. Ironically, these criteria -- resources and eugenics -- are exactly those used by the now-discredited state programs.

What standard should Illinois courts use to resolve cases like Johnson's? To be blunt, families give up a lot to care for a cognitively impaired child. Is it so wrong to ask the disabled individual to give up the right have children in return? Might this be a fair exchange?

Absolutely not. The law says no person's reproductive options are contingent on the needs, desires or judgment of another. Why should persons with disabilities be the exception? No parent is allowed to control whether their child bears a grandchild, even when they're a minor (legally "incompetent").

Wives can give birth and have abortions against their husband's wishes. And the Supreme Court has ruled that criminals can't be sterilized as part of their punishment.

Reproductive freedom holds such a cherished place in our society that even the welfare of the potential child does not trump it. The state cannot prevent an abusive, drug-addicted person who has lost eight children to foster care from procreating.

But Judge James Riley sees this case differently. In his Aug. 11 decision, he ruled that it is in Kirsten's best interest 'to have a permanent form of birth control. Why? Because several people testified that she would not be able to care for a child alone.

This sounds like a "parental litmus test" to me. I'm not applauding irresponsible parenting, but making people with disabilities the only group in America that must prove they'll be good parents before they are "allowed" to reproduce is intolerable discrimination.

The second reason Riley gave for his decision was Johnson "would suffer irreparable psychological damage" if she had a child and the child was removed from her because of her inability to care for that child.

## **She can read, not drive**

No one, including Johnson, disputes she'd need training and support to be a good parent. She's high functioning in some ways, but her IQ is in the borderline to low average range. She can dress, bathe and feed herself, but she can't drive. She can read, but she can't handle financial affairs, and she needs some assistance with household chores. But information and services for disabled parents is available at places like Community Support Services. Parenting support for the cognitively impaired is like ramps for those in wheelchairs -- small modifications that ensure the only limitations are those caused by disability itself, not our society's response to it.

This case highlights the deep chasm that separates the able-bodied from the disabled. To prove it, try a thought experiment: Who in this essay have you identified with so far? I know I imagine myself in the position of the well-intentioned, overwhelmed guardian. If I stretch, I can imagine what it might be like to be raised by a cognitively impaired mother. Both sound hard.

But it's telling that I don't imagine myself in the shoes of the disabled person. It's also foolish. Johnson's brain was injured in childhood when she was hit by a car, something that could happen to me tomorrow. And if it did, I'd want to live my life to its fullest. I'd want "the dignity of risk" -- the

option to try difficult things and live with the consequences -- and the support I'd need to maximize my potential and happiness. That's my "living will" for the social care I'd want after an accident.

Johnson's case isn't over. Riley has ordered that Johnson be evaluated to see whether she's a medical candidate for Implanon (the new Norplant) or an IUD that last 5 or 10 years, and he deferred to January his final ruling on Ms. Howse's petition for tubal ligation.

In this precedent-setting case, Riley says he's following a Pennsylvania court that adopted a "discretionary best interest standard." But his application of the specified best interest criteria is misguided and incomplete, because the standard the Pennsylvania court used is intended to focus the court on what's best for the person with a disability, and away from the best interest of the guardian, family, society or potential children.

Persons with disabilities in Illinois deserve better than this. Tubal ligation is a safe, effective form of contraception many women -- including some with cognitive deficits -- freely choose. But allowing guardians to permanently block their ward's reproductive desires with the muscle of the courts and the knife of medicine is a discriminatory step back toward a shameful era to which we should never return.

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