

## DISABILITY AND THE DUTIES OF POTENTIAL PARENTS

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### I. INTRODUCTION

Potential parents face an ever-expanding array of choices about whether, when, and how to have children. Of particular ethical concern to disability scholars are reproductive genetic technologies that give potential parents control over the characteristics of their future children.<sup>1</sup> These technologies enable potential parents to select for or against particular traits, including traits considered to be disabling.<sup>2</sup> This possibility raises many questions about the ethical implications of such choices.

This article first considers one possible position on disability and the use of reproductive genetic technologies (RGTs) based upon the Strong Claim, and argues that there are at least several reasons to believe that it is a plausible view. This article then describes and critically evaluates a family of objections to claims such as the disability rights critique and offers several conclusions about how these perspectives should be balanced by potential parents making reproductive choices.

### II. THE STRONG CLAIM EXPLAINED

The Strong Claim provides that potential parents are morally required to use reproductive genetic technologies to reduce the likelihood that their future children will have a serious disability when the burdens of doing so are reasonable. Before discussing the Claim's plausibility, it is helpful to clarify what, precisely, the Strong Claim contends. First, the Strong Claim

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1. Ronald M. Green, *Parental Autonomy and the Obligation Not to Harm One's Child Genetically*, 25 J.L. MED. & ETHICS 5, 5 (1997).

2. Dan W. Brock, *The Non-Identity Problem and Genetic Harms - The Case of Wrongful Handicaps*, 9 BIOETHICS 269, 269-70 (1995) (discussing, for example, screening for "diseases and conditions less severe or grave as to be compatible with having a life worth living.").

states that parents can be *morally required* to use RGTs. The Claim, therefore goes a step beyond suggesting that it is morally permissible for potential parents to use these technologies—a relatively weak (and less controversial) claim. By stating that parents are morally obligated to use RGTs under certain circumstances, the Strong Claim proposes a normative guide for potential parents making decisions about reproduction. Importantly, however, the Strong Claim does not advocate any legal restrictions or requirements for potential parents. The moral correctness of a choice may be one factor that helps determine whether that choice should be legally forbidden, permitted, or required, but this factor must be balanced alongside numerous other considerations. The Strong Claim therefore in no way entails that potential parents should be legally required to use RGTs under any circumstances.

RGTs combine assisted reproductive technologies and genetic technologies to enable potential parents to influence the characteristics of the children they may conceive.<sup>3</sup> There are several types of RGTs currently available to potential parents.<sup>4</sup> Prior to conception, genetic testing of oocytes is possible for some traits via polar body analysis.<sup>5</sup> For example, polar bodies can be removed from an in vitro oocyte (just after insemination but before the genetic material from the gametes merge) and tested for the presence of the extra chromosomes that cause trisomies 13, 18, and 21.<sup>6</sup> In contrast, genetic testing cannot be performed on sperm before conception because such testing involves the destruction of the cells.<sup>7</sup> However, sperm sorting, in which sperm carrying an X chromosome are separated from those carrying a Y chromosome, can be used to select the sex of the future child.<sup>8</sup> Potential parents may choose to use this technology

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3. Janet Malek, *Understanding Risks and Benefits in Research on Reproductive Genetic Technologies*, 32 J. MED. & PHIL. 339, 341-42 (2007).

4. *Id.* (examples of RGTs include sperm sorting, preconception genetic diagnosis, and preimplantation genetic diagnosis).

5. M. Durban et al., *PGD in Female Carriers of Balanced Robertsonian and Reciprocal Translocations by First Polar Body Analysis*, 7 HUM. REPRODUCTION UPDATE 591, 591-92 (2001).

6. See, e.g., S.A. Gitlin et al., *Oocyte Biology and Genetics Revelations from Polar Bodies*, 6 REPRODUCTIVE BIOMEDICINE ONLINE, 403, 404-08 (2003); Nat'l Inst. of Health, Stem Cell Information, at <http://stemcells.nih.gov/info/glossary.asp> (last visited Jan. 7, 2009) (defining "polar body" and describing how it undergoes meiosis); M. Plachot, *Genetic Analysis of the Oocyte – A Review*, 24 PLACENTA (SUPPLEMENT 2) S66, S67-68 (2003) (describing one test for analyzing polar bodies and abnormalities in chromosomes 13, 16, 18, 21, and 22).

7. Y. Verlinky & C.M. Strom, *Preconception Diagnosis of Polar Bodies, Preconception & Preimplantation Diagnosis of Human Genetic Disease* 233, 233 (Robert G. Edwards, ed., 1993).

8. Bonnie Steinbock, *Sex Selection: Not Obviously Wrong*, in REPROD. TECHNOLOGIES: A READER 57, 58-59 (Thomas A. Shannon ed., 2003); see Edgar Dahl et al., *Preconception Sex*

to increase the likelihood that they have a girl, for example, in order to prevent their future child from having an X-linked genetic disorder such as Lesch-Nyhan Syndrome.<sup>9</sup>

A broader array of genetic tests can be used after conception.<sup>10</sup> Embryos created as a result of in vitro fertilization can be tested using preimplantation genetic diagnosis (PGD) to determine which embryos will be implanted in a potential mother's uterus.<sup>11</sup> PGD involves the removal and genetic analysis of a single cell from each available embryo, so only those embryos that do not carry a particular gene, such as the gene for Huntington's disease, can be selected for implantation.<sup>12</sup> Additionally, prenatal diagnosis via amniocentesis, chorionic villus sampling, and other methods can be used to test developing fetuses for many genetic conditions including cystic fibrosis, Tay Sachs disease, and spina bifida.<sup>13</sup> Although these different types of RGTs raise different ethical issues, each may be used to reduce the likelihood that a future child will be affected by a disabling condition. Acceptance of the Strong Claim, therefore, could require the use of any of these technologies.

The term "future child" in the Strong Claim refers to a child who may come into being as a result of its potential parents' reproductive decisions. The term is not meant to denote anything about the moral status of that entity or to equate it with existing children. The concept of a "serious

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*Selection Demand and Preferences in the United States*, 85 FERTILITY & STERILITY 468, 468 (2006).

9. Lawrence J. Nelson, *Preimplantation Diagnosis*, 30 CLINICS IN PERINATOLOGY 67, 76 (2003); see also Steinbock, *supra* note 8.

10. See Am. Ass'n for Clinical Chemistry, Lab Tests Online, Pregnancy & Prenatal Testing, at <http://labtestsonline.org/understanding/wellness/pregnancy.html> (last visited Jan. 7, 2009). For example, genetic testing for inherited diseases, hemoglobin disorders, and cystic fibrosis carriers can be performed before or after conception, whereas testing for fetal abnormalities and risks such as Down syndrome screening, triple or quad marker screening, chronic villus sampling, amniocentesis, and cordocentesis can be performed after conception. *Id.*

11. Reprod. Health Tech. Project, Pre-Implantation Genetic Diagnosis, Fact Sheet, at [www.rhttp.org/fertility/documents/PGDFactSheet.doc](http://www.rhttp.org/fertility/documents/PGDFactSheet.doc) (last visited Jan. 7, 2009); see also JON W. GORDON, THE SCIENCE AND ETHICS OF ENGINEERING THE HUMAN GERM LINE: MENDEL'S MAZE 174 (2003).

12. Reprod. Health Tech. Project, *supra* note 11; GORDON, *supra* 11.

13. See, e.g., AM. SOC'Y FOR REPROD. MED., PATIENT'S FACT SHEET, GENETIC SCREENING FOR BIRTH DEFECTS (2005), available at [www.asrm.org/Patients/FactSheets/genetic\\_screening.pdf](http://www.asrm.org/Patients/FactSheets/genetic_screening.pdf) (last visited Jan. 7, 2009); see also Nat'l Inst. of Neurological Disorders & Stroke, Spina Bifida Fact Sheet (2007), available at [www.ninds.nih.gov/disorders/spina\\_bifida/detail\\_spina\\_bifida.htm](http://www.ninds.nih.gov/disorders/spina_bifida/detail_spina_bifida.htm) (last visited Jan. 7, 2009) (explaining the use of amniocentesis for prenatal diagnosis of spina bifida); see also Cynthia M. Powell, *The Current State of Prenatal Genetic Testing in the United States*, in PRENATAL TESTING AND DISABILITY RIGHTS 44, 47 (Erik Parens & Adrienne Asch eds., 2000) (describing additional procedures required for definitive diagnosis of neural tube impairments or chromosome abnormalities).

disability” plays a central role in the Strong Claim. Jonathan Glover argues that “[d]isability requires failure or limitation of functioning. But a limitation of functioning creates disability only if (on its own or *via* social discrimination) it impairs capacities for human flourishing.”<sup>14</sup> That is, for a condition to be correctly classified as a disability, two conditions must be met: first, a disability must involve a departure from “normal human functioning”;<sup>15</sup> second, that departure has to negatively affect the individual’s opportunity to pursue “a good human life”.<sup>16</sup> Although there may be significant disagreement as to what humans require to flourish or live a good life, there may be less disagreement about the capacities needed for individuals to pursue that goal.<sup>17</sup> When these capacities are compromised, the future child will face greater challenges in pursuing a good life. The inclusion of the qualifier “serious” in the Strong Claim creates room for interpretation that makes the scope of the Claim somewhat ambiguous. Disabilities cannot be dichotomously classified as serious or not serious; rather, each disability falls somewhere along a continuum of seriousness. Where to draw the line differentiating serious from non-serious disabilities along that continuum is a matter for debate at another time. For the purposes of this article, it is sufficient to identify paradigm conditions that clearly fall into the “serious” category. Conditions such as Tay-Sachs disease and Trisomy 13 are unquestionably serious disabling conditions.<sup>18</sup> Cystic fibrosis and fragile X syndrome may also cause serious disabilities.<sup>19</sup> These conditions and others that diminish a future child’s “capacities for human flourishing”<sup>20</sup> to an equivalent extent are therefore covered by the Strong Claim.

Finally, the Strong Claim only applies to cases in which the *burdens* of using RGTs are reasonable.<sup>21</sup> The financial and emotional costs associated

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14. JONATHAN GLOVER, CHOOSING CHILDREN: GENES, DISABILITY, AND DESIGN 9 (2008).

15. *Id.* at 11.

16. *Id.*

17. *See id.* at 10.

18. *See* Nat’l Inst. of Neurological Disorders & Stroke, Tay-Sachs Disease Information Page, at [www.ninds.nih.gov/disorders/taysachs/taysachs.htm](http://www.ninds.nih.gov/disorders/taysachs/taysachs.htm) (last visited Jan. 7, 2009) [hereinafter NINDS Tay-Sachs Information]; *see also* U.S. Nat’l Libr. of Med., Genetics Home Reference, Trisomy 13, at <http://ghr.nlm.nih.gov/condition=trisomy13> (last visited Jan. 7, 2009).

19. *See* U.S. Nat’l Libr. of Med., Medline Plus, Cystic Fibrosis, at [www.nlm.nih.gov/medlineplus/print/cysticfibrosis.html](http://www.nlm.nih.gov/medlineplus/print/cysticfibrosis.html) (last visited Jan. 7, 2009); *see also* U.S. Nat’l Libr. of Med., Medline Plus, Fragile X Syndrome, at [www.nlm.nih.gov/medlineplus/print/fragilex\\_syndrome.html](http://www.nlm.nih.gov/medlineplus/print/fragilex_syndrome.html) (last visited Jan. 7, 2009).

20. GLOVER, *supra* note 14.

21. *See* Powell, *supra* note 13, at 50 (describing the risks of prenatal diagnostic procedures); *see also* Mayo Found. for Med. Educ. and Res., Prenatal Testing: Should You Consider It?, at [www.mayoclinic.com/health/prenatal-testing/PR00014](http://www.mayoclinic.com/health/prenatal-testing/PR00014) (last visited Jan. 7,

with the use of these technologies can be significant. To evaluate their reasonableness, the burdens must be estimated relative to the expected benefits. The Strong Claim does not apply if the burdens of using RGTs are too high relative to the expected benefits. In other words, the anticipated benefits of employing RGTs must be significant and likely enough to outweigh the anticipated costs of using the technology. It would be impossible to develop a comprehensive list of specific situations in which this condition is met. However, multiple variables are relevant to this determination, including: the condition in question (such as inheritance, severity, expressivity, and penetrance), the type of technology being considered (whether it involves pre-conception selection, PGD, or prenatal diagnosis), and characteristics of the potential parents (such as their age, financial situation, and other moral beliefs).<sup>22</sup>

### III. DEFENDING THE STRONG CLAIM

At least three arguments can be made in support of the Strong Claim as defined, *supra*. Although this article focuses on the disability rights critique of the Strong Claim, it seems appropriate to articulate why the Strong Claim and other similar claims are plausible. The Strong Claim is supported by the validity of promoting the well-being of future children. By Glover's definition, disabilities are conditions that limit individuals' "capacities for human flourishing."<sup>23</sup> By its nature, human flourishing—however it is understood—is good for people. Thus, future children are better off if their opportunity to pursue a good life is not limited by disability. The choice to use RGTs to prevent disability therefore promotes future children's well-being because that choice makes it more likely that those future children will be able to flourish.

Some authors maintain that arguments about future children's well-being do not make sense when applied to decisions about an individual future child.<sup>24</sup> They claim that it is not possible to improve the well-being of a particular child by using RGTs because the use of these technologies affects the identity of the individual brought into being.<sup>25</sup> In other words,

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2009); U.S. Nat'l Libr. of Med., Genetics Home Reference, What Are the Risks and Limitations of Genetic Testing?, at <http://ghr.nlm.nih.gov/handbook/testing/riskslimitations> (last visited Jan. 7, 2009).

22. See U.S. Nat'l Libr. of Med., Medline Plus, Prenatal Testing, at [www.nlm.nih.gov/medlineplus/print/prenataltesting.html](http://www.nlm.nih.gov/medlineplus/print/prenataltesting.html) (last visited Jan. 7, 2009) (describing the patient population appropriate for prenatal testing); see also Mayo Found. for Med. Educ. and Res., *supra* note 21 (describing screening and diagnostic tests); U.S. Nat'l Libr. of Med., *supra* note 21 (describing factors to be considered when contemplating prenatal testing).

23. GLOVER, *supra* note 14.

24. See, e.g., DEREK PARFIT, REASONS AND PERSONS 356-57 (1989).

25. *Id.* at 202.

when a potential parent chooses to use RGTs to conceive a child, that decision changes the genetic identity of the child conceived. The child who would otherwise have been conceived, therefore, is no better off as a result of the potential parent's choice because, due to that decision, he or she does not exist. Even if one is persuaded by this argument, the Strong Claim can still be defended on the grounds that it promotes the well-being of future children. Rather than claiming that the use of RGTs promotes a particular child's well-being, it can be claimed that the use of these technologies promotes the well-being of future children as a group.<sup>26</sup> Understood this way, potential parents can make the class of future children better off by using RGTs to prevent disability.

Although the claim that potential parents are morally required to make their future children better off is intuitively plausible whether future children are considered individually or as a group, the Strong Claim can also be supported by a second argument that focuses on the nature of the relationship between parents and children.

Parents have a special set of obligations to their children. The choice to bring a person into being generates responsibilities for the individual making that choice. As a result of being created, children are vulnerable to a variety of harms that they would not otherwise be at risk of experiencing (because they otherwise would not have existed). Parents have a moral obligation to attempt to mitigate this vulnerability whenever possible because their decision to conceive creates it. Using RGTs to prevent serious disabilities is one way of reducing future children's vulnerability to harm and therefore is one way that potential parents can fulfill this obligation. All other things being equal, a future child who has a serious disability is at a greater risk of experiencing pain, suffering, and other harms due to his or her limited capabilities compared to a future child who does not.<sup>27</sup> Thus it may be argued that reducing the likelihood that a future child will have such a disability is morally required by the special nature of the parent-child relationship.

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26. Brock, *supra* note 2, at 271-72.

27. See, e.g., Mayo Found. for Med. Educ. and Res., Children's Health: Down Syndrome, at [www.mayoclinic.com/health/downsyndrome/DS00182/DSECTION=complications](http://www.mayoclinic.com/health/downsyndrome/DS00182/DSECTION=complications) (last visited Jan. 7, 2009) (explaining that children with Down syndrome often have an increased likelihood of developing life-threatening heart problems, leukemia, infectious disease, and dementia); NINDS Tay-Sachs Information, *supra* note 18 (noting that children with Tay-Sachs experience a relentless deterioration of mental and physical abilities, become blind, deaf, and paralyzed, and usually die by age four); Nat'l Inst. of Neurological Disorders and Stroke, Lesch-Nyhan Syndrome Information Page at [www.ninds.nih.gov/disorders/lesch\\_nyhan/lesch\\_nyhan.htm](http://www.ninds.nih.gov/disorders/lesch_nyhan/lesch_nyhan.htm) (last visited Jan. 7, 2009) (explaining that children who inherit Lesch-Nyhan syndrome have symptoms including severe gout, poor muscle control, moderate retardation, and self-mutilating behaviors, and often die due to renal failure before the age of twenty).

Finally, the plausibility of the Strong Claim can be supported by a third line of reasoning. The requirement for potential parents to use RGTs under some circumstances can be defended by analogy to paradigm cases of parental responsibility. Parents are morally (and legally, in many cases) required to use car seats for their children when driving with them in the car.<sup>28</sup> They are expected to provide adequate nutrition, clothing, and shelter for their children.<sup>29</sup> And they are obligated to seek proper medical care when their children are affected by treatable medical conditions.<sup>30</sup> All of these paradigm imperatives protect children from limitations on their capacity to pursue a good life. RGTs provide another method by which potential parents can seek to reduce their future children's likelihood of experiencing such limitations. Therefore, requiring parents to use RGTs to prevent disability, at least under some circumstances, would be consistent with the argument that parents are morally required to take the above-mentioned precautions for their children.

These three arguments suggest that the Strong Claim is plausible. As may be expected, a number of objections have been raised to claims like the Strong Claim.<sup>31</sup> Reviewing and analyzing all of these objections is far beyond the scope of this article and the focus of this journal issue. Thus, the following discussion will present and evaluate one important subset of these objections.

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28. See, e.g., MO. REV. STAT. § 307.179 (2008); MASS. GEN. LAWS ch. 90, § 13A (2008); CAL. VEH. CODE § 27315 (2008) (Missouri, Massachusetts, and California are examples of states that require all passengers under age 16 to wear a safety belt); see also Ins. Inst. for Highway Safety, Highway Loss Data Inst., Child Restraint Laws, at [www.iihs.org/laws/ChildRestraint.aspx](http://www.iihs.org/laws/ChildRestraint.aspx) (last visited Jan. 7, 2009) (summarizing the child restraint laws for all fifty states).

29. See generally Catherine S. Taylor, *Children's Right to an Adequate Standard of Living*, CHILD. LEGAL RTS. J., Summer 2002, at 17, 17-20 (summarizing the fifty-four provisions under Article 27 of the United Nations Convention on the Rights of the Child, which includes basic nutrition, clothing, and housing); see also JOHN E.B. MYERS, EVIDENCE IN CHILD ABUSE & NEGLECT CASES 337 & n.267 (3rd ed. 1997) (referencing *People v. Rippberger*, 231 Cal. App. 3d 1667, 1687-88, (1991) (holding that parents have a legal duty to maintain their children that includes proper nutrition and shelter)).

30. See, e.g., MYERS, *supra* note 29, at 337-43 & n.269 (referencing *Commonwealth v. Twitchell*, 617 N.E. 2d 609, 612 (Mass. 1993) (holding that "parents have a duty to seek medical attention for a child"); *In re Faridah W.*, 579 N.Y.S. 2d 377, 378 (1992) (holding that a parent has a "non-delegable affirmative duty to provide a child with adequate medical care, which has been determined to be that degree of care exercised by ordinarily prudent loving parents who are anxious for the well-being of their child.")).

31. See, e.g., Erik Parens & Adrienne Asch, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, 29 HASTINGS CENTER REP., July-Aug. 1999, at S2.

### A. *The Expressivist Argument*

The expressivist argument is a cornerstone in the family of objections to views like the Strong Claim known collectively as the “disability rights critique.”<sup>32</sup> According to the expressivist argument, when potential parents use RGTs to select against disabling conditions in their future children, they express something negative to and about people living with those conditions.<sup>33</sup> Such choices send the discriminatory message to these individuals that their lives are less worthwhile than the lives of people who do not live with disabilities.<sup>34</sup> Adrienne Asch explains that the use of RGTs to prevent disability in future children is morally problematic because

this one characteristic of the embryo or fetus is the basis for the decision not to continue the pregnancy or to implant the embryo. That decision . . . concludes that one piece of information about a potential child suffices to predict whether the experience of raising that child will meet parental expectations.<sup>35</sup>

In other words, the use of these technologies lets one single characteristic represent the entire person, sending the hurtful message that the only relevant trait of those who live with disabilities is the disability itself.<sup>36</sup> If this argument is sound, accepting something like the Strong Claim would be morally problematic because it communicates this hurtful message by advocating the use of RGTs to reduce the likelihood that future children will have a disability.

The soundness of the expressivist argument can be challenged by at least three lines of reasoning. First, its conclusion can be refuted on semantic grounds. It is not clear that the choice to use RGTs to reduce the likelihood that a future child will have a disability sends *any* message to or about existing people living with disabilities. The choice to use RGTs, in and of itself, may communicate nothing at all. James Lindemann Nelson argues that in order for an action to send any kind of message, the action must have a publicly accepted meaning.<sup>37</sup> Unless this type of connection between an action and a message exists, the action itself communicates nothing.<sup>38</sup> The choice to use RGTs does not seem to have any such agreed-

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32. *See id.*

33. *Id.*

34. *Id.*

35. Adrienne Asch, *Why I Haven't Changed My Mind About Prenatal Diagnosis: Reflections and Refinements*, in *PRENATAL TESTING & DISABILITY RIGHTS* 234, 236 (Erik Parens & Adrienne Asch eds., 2000).

36. Parens & Asch, *supra* note 31, at S2.

37. James Lindemann Nelson, *Prenatal Diagnosis, Personal Identity, and Disability*, 10 *KENNEDY INST. OF ETHICS J.* 213, 216–17 (2000).

38. *Id.* at 217 (stating that a behavior must have “semantic significance”).



upon meaning, and thus that choice itself expresses nothing at all.<sup>39</sup> Further, even if the choice to use RGTs was publicly associated with some meaning, that meaning may be unrelated to the value of the lives of existing or future people with disabilities. That choice may instead communicate something about the individuals making reproductive decisions or something about the particularities of their situation. Potential parents choose to use RGTs for a variety of reasons, many of which have nothing to do with the value of the lives of people who live with disabling conditions.<sup>40</sup>

Second, the expressivist argument is problematic because it proves too much. If using RGTs to prevent disability in future children is morally objectionable because it sends a negative message about those living with a disability, it seems to follow that the use of *other* methods of preventing disability in children would also be morally objectionable for the same reason. For example, many parents choose to vaccinate their children to prevent diseases that would limit their future opportunities.<sup>41</sup> However, the conclusion that a parent's choice to give his or her child a vaccine against a particular disease sends a negative message to or about those people living with that disease is intuitively implausible. Therefore, if the expressivist argument leads to this conclusion, the argument must be unsound.

Supporters of the expressivist argument have responded to this criticism by claiming that RGTs are importantly different from other methods of preventing disability.<sup>42</sup> Methods such as medical treatment, vaccination, and prevention education target one particular threat to the individual while respecting the other traits that constitute that individual's identity.<sup>43</sup> In contrast, the use of RGTs currently requires the acceptance or rejection of whole gametes, embryos, or fetuses based on a single characteristic,

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39. *Id.*

40. See Allen Buchanan, *Choosing Who Will Be Disabled: Genetic Intervention and the Morality of Inclusion*, 13 SOC. PHIL. & POL'Y, Summer 1996, 18, 45-46; see also Colin Gavaghan, *Right Problem, Wrong Solution: A Pro-Choice Response to "Expressivist" Concerns About Preimplantation Genetic Diagnosis*, 16 CAMBRIDGE Q. OF HEALTHCARE ETHICS 20, 25 (2006).

41. See Ctrs. for Disease Control & Prevention, *Why Immunize?*, at [www.cdc.gov/vaccines/vac-gen/why.htm](http://www.cdc.gov/vaccines/vac-gen/why.htm) (last visited Jan. 7, 2009) (describing the future benefits which result from vaccine use); see Ctrs. for Disease Control & Prevention, *What Would Happen If We Stopped Vaccinations?*, at [www.cdc.gov/vaccines/vac-gen/whatifstop.htm](http://www.cdc.gov/vaccines/vac-gen/whatifstop.htm) (last visited Jan. 7, 2009) (describing the benefits of vaccines).

42. Erik Parens & Adrienne Ash, *The Disability Rights Critique of Prenatal Genetic Testing: Reflections and Recommendations*, in *PRENATAL TESTING AND DISABILITY RIGHTS* 3, 16 (Erik Parens & Adrienne Asch eds., 2000). Other methods of preventing disabilities include "taking folic acid to reduce the likelihood of spina bifida or eschewing medication that is known to stunt the growth or harm the organs or limbs of a developing fetus." *Id.*

43. See *id.* (explaining that the use or nonuse of some other methods of preventing disability are designed to protect the developing fetus).

thereby dismissing the value of that entity's other identity-determining traits.<sup>44</sup>

This line of reasoning fails because it relies on an overly simplistic understanding of individual identity. An in-depth analysis of the various theories of identity is outside the scope of this article; however a brief summary of two possible rebuttals may be helpful. Nelson has argued that the use of non-RGT methods of preventing disability may, in fact, alter the identities of the individuals on whom they are used.<sup>45</sup> The use of such methods could affect the individuals' genetic structures or their life experiences to such a significant extent that they become, in a morally relevant sense, different people.<sup>46</sup> If this is true, almost any approach to preventing disability would constitute a rejection of an entire individual and not only the rejection of a particular trait.<sup>47</sup> An alternate rebuttal is the opposite view: that neither RGTs nor other methods of preventing disability change the identity of the future child in a morally relevant sense. The identities of future children should be understood in a way that creates continuity among a potential parent's genetically distinct possible future children.<sup>48</sup> If the choice to use RGTs to prevent disability is not viewed as identity-determining, that choice may express disvalue for the particular trait being prevented but not for the individual who has that trait.<sup>49</sup> Regardless of which understanding of identity is used, if either of these rebuttals is sound, RGTs are not different from other methods of preventing disability in the way that supporters of the expressivist argument need them to be.

Third, the expressivist argument can be refuted on grounds that there is at least one morally relevant difference between future children and existing people: existing people have full moral status while future children do not.<sup>50</sup>

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44. *See id.* at 15.

45. Nelson, *supra* note 37, at 221.

46. *Id.* at 223-24.

47. *Id.* at 224-25.

48. Janet Malek, *Identity, Harm, and the Ethics of Reproductive Technology*, 31 J. MED. & PHIL. 83, 91-92 (2006). This argument is more intuitively appealing for some types of RGTs than for others. When choosing among gametes to use in creating a child, it is easier to see the various genetically distinct possible children as one "future child" than to do so in the context of prenatal testing. Nonetheless, this continuity of identity is possible in both contexts.

49. *See generally id.* at 90-92 (discussing a child's "narrative identity" as consisting of not just one particular trait, but as many traits and narratives that all evolve into the narrative identity).

50. Laurence B. McCullough & Frank A. Chervenak, *A Critical Analysis of the Concept and Discourse of 'Unborn Child'*, 8 AM. J. BIOETHICS, 34, 36 (2008). A key piece of the disability rights critique is that using RGTs with the intention of preventing disability is morally problematic in a way that making reproductive choices for other reasons is not. Therefore, it would not be inconsistent for a supporter of the expressivist argument to agree with this statement.

While moral status may be voluntarily conferred upon future children, it can also be withheld, at least until the fetus becomes viable.<sup>51</sup> Once an entity gains (or is given) full moral status, that entity must be respected as a unique individual with a complete set of defining characteristics.<sup>52</sup> However, this is not necessarily true for future children.<sup>53</sup> Choices involving future children are therefore fundamentally different from those involving existing individuals. As a result of this difference, the argument that making choices about future children communicates something about the lives of certain existing individuals requires a logical jump that cannot be defended.

These three refutations of the expressivist argument raise serious doubts about its conclusions. It therefore provides little evidence that the Strong Claim and similar claims are morally problematic. Disability rights advocates, however, have formulated two other disability-based arguments against claims like the Strong Claim: the "Parental Attitudes Argument" and the "Loss of Support Argument."

#### *B. The Parental Attitudes Argument*

A second piece of the disability rights critique is the assertion that the Strong Claim promotes undesirable attitudes of potential parents toward parenthood.<sup>54</sup> Asch and Parens contend that, "[g]ood parents will care about raising whatever child they receive and about the relationship they will develop, not about the traits the child bears."<sup>55</sup> The Strong Claim runs counter to this position, advocating that parents make choices to select against particular traits in their future children rather than embracing whichever traits the "natural" process would otherwise select. If potential parents are morally required to use RGTs to prevent disability in future children, they will look at those future children differently, viewing them through a lens of judgment instead of unconditional acceptance.<sup>56</sup> These technologies therefore promote inappropriate attitudes toward parenthood on the part of potential parents.

One response to this argument takes the same approach as the second refutation of the expressivist argument, discussed above. If using RGTs to prevent disability in future children encourages undesirable parental

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51. *Id.* at 35-39.

52. *Id.* at 37.

53. *See id.* at 38.

54. Parens & Asch, *supra* note 31, at S5.

55. *Id.* at S6.

56. *See* PRESIDENT'S COUNCIL ON BIOETHICS, REPRODUCTION AND RESPONSIBILITY: THE REGULATION OF NEW BIOTECHNOLOGIES 96 (2004), *available at* [www.bioethics.gov/reports/reproductionandresponsibility/\\_pcbe\\_final\\_reproduction\\_and\\_responsibility.pdf](http://www.bioethics.gov/reports/reproductionandresponsibility/_pcbe_final_reproduction_and_responsibility.pdf) (last visited Jan. 7, 2009).

attitudes, would using other methods of preventing disability have the same effect? A defender of the parental attitudes argument might claim that these two types of disability prevention methods are fundamentally different because using RGTs changes the identity of the future child whereas other prevention methods do not. As argued previously, this response is not convincing because depending on the theory of personal identity used, it could equally be the case that both types of methods change the future child's identity, or that neither does.<sup>57</sup>

Secondly, the parental attitudes argument assumes that unconditional acceptance of a future child as a whole requires the unconditional acceptance of each of that future child's traits. This assumption clearly seems unjustified, as it is possible for a parent (or sibling or spouse) to have unconstrained love and complete acceptance for a child (or sibling or spouse) without embracing each of their specific qualities. Parents work to shape children's behavior (and couples work through differences) even though they would not love their children (or spouses) any less if those efforts were to fail. In the same way, potential parents may use RGTs as a way of reducing the likelihood that their future children will have a disability, but nonetheless may love them just much if the child is born with a disability. A general assumption that an attempt to alter the traits of a future child reflects a conditional acceptance of the future child therefore cannot be defended, even if it may be correct in some cases.

A third response to the parental attitudes argument raises questions about another assumption integral to that position. William Ruddick argues that there are various legitimate concepts of conception, pregnancy, and parenthood.<sup>58</sup> The parental attitudes argument's presumption that the only morally justifiable paradigm for these projects is unconditional acceptance is therefore mistaken.<sup>59</sup> Other paradigms in which the future child is viewed as the result of a maternal project or in which the good of the family as a whole is prioritized may also be morally acceptable.<sup>60</sup> If so, the parental attitudes argument assumes the moral correctness of an overly simplistic and possibly inaccurate understanding of what conception, pregnancy, and parenthood are about.

This line of thought can be taken further to suggest that morally correct attitudes toward parenthood actually support, and perhaps require, the use of RGTs to prevent disability in future children. Unconditional acceptance is

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57. See *supra* notes 41-49 and accompanying text.

58. See Parens & Asch, *supra* note 42, at 17-19.

59. *Id.* at 18.

60. See *id.* at 19 (for example, a "projectivist" or "familial" paradigm "is compatible with trying to ensure that any child they raise has characteristics that accord with these parental goals.").

not the only criterion upon which parental attitudes should be evaluated. A desire to help one's children be the best they can be is also a feature of laudable parental attitudes. In fact, parents who do not work to give their children the tools they need to pursue a good human life are considered to have a negligent approach to parenting.<sup>61</sup> On this criterion, then, the choice to use RGTs to prevent disability in future children is squarely in line with appropriate parental attitudes. Although it is possible for one of these criteria to be met to the exclusion of the other, a balance between the two is not only acceptable but morally desirable.

### C. *The Loss of Support Argument*

A third disability rights-based objection to claims like the Strong Claim is the "loss of support" argument.<sup>62</sup> According to this position, if RGTs are routinely used to reduce the likelihood that future children will be affected by disability, the community of people living with disability will shrink.<sup>63</sup> Proponents of this argument maintain that as the numbers of people living with disability become smaller, "public support for those who have disabilities will dwindle."<sup>64</sup> Fewer resources will be allocated for disability accommodation and support for these accommodations will become insufficient to preserve them.<sup>65</sup>

As Allen Buchanan and colleagues note, the soundness of the loss of support argument depends on empirical evidence that is currently unavailable.<sup>66</sup> As an initial matter, the effect of the widespread acceptance of the Strong Claim on individuals living with a disability is unknown.<sup>67</sup> Further, there are many different causes of disabling conditions.<sup>68</sup> Conditions for which a genetic test is available are only one such cause; individuals also acquire disabilities through events that happen during and

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61. See generally *id.* (explaining that some parents view their child's outcome as a reflection of their own parenting skills); Ruthbeth Finerman, *'Parental Incompetence' and 'Selective Neglect': Blaming the Victim in Child Survival*, 40 SOC. SCI. MED. 5, 11 (1995).

62. ALLEN BUCHANAN ET AL., FROM CHANCE TO CHOICE: GENETICS AND JUSTICE 266 (2000).

63. *Id.*

64. *Id.*

65. *Id.* at 266–68. For example, "[w]hen the number of individuals suffering from a particular malady is small enough, it may not be profitable for pharmaceutical companies to produce drugs valuable to these individuals." *Id.* at 268.

66. *Id.* at 266.

67. BUCHANAN ET AL., *supra* note 62 at, 266–67.

68. See generally *id.* at 268 (discussing blindness as a result of contact with gonococcus bacteria during vaginal delivery); Alta California Regional Ctr., *Causes of Developmental Disabilities*, at [www.altaregional.org/whoWeServe/causesOfDisabilities/](http://www.altaregional.org/whoWeServe/causesOfDisabilities/) (last visited Jan. 7, 2009) (listing nine different causes of developmental disabilities).

after birth.<sup>69</sup> It seems unlikely, therefore, that the numbers of people living with disabilities would be radically reduced as a result of general acceptance of the Strong Claim. Second, even if the numbers of individuals living with disabilities were to diminish significantly, it is unclear what effect that change would have on the practice of accommodation.<sup>70</sup> While it does seem possible that support for those living with disabilities could be reduced as a result of the widespread use of RGTs, it is equally possible that this would not be the case. If RGTs were widely used to prevent disabilities, those who have a disability could in fact be *better* accommodated because the available resources could be used to assist fewer individuals. The existing social imperative to provide accommodations for those living with disabilities is not based on a cost-benefit analysis demonstrating that these accommodations are worthwhile investments because of the numbers of individuals who benefit from them. Instead, these accommodations are justified by reference to the rights of those individuals living with disabilities and to the demands of justice. As a result, the existing imperative to accommodate the disabled is unlikely to be affected by the number of individuals who are members of that community and it seems possible that the level of support for those living with disabilities would increase, or at least remain unchanged.

A slightly different, perhaps more plausible, version of the loss of support argument could be articulated as follows: acceptance of the Strong Claim could create a public perception that disabilities are the result of parental choice. If such disabilities are viewed as the result of individuals' voluntary choices rather than as a result of the random natural lottery, the argument that those disabilities must be accommodated could be undermined. Such a shift in the public's attitude toward those who are born with disabilities could result in a decrease in the services made available to individuals born with disabilities. As Michael Sandel has eloquently suggested, "the explosion of responsibility for our own fate, and that of our children, may diminish our sense of solidarity with those less fortunate than

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69. See generally BUCHANAN ET AL., *supra* note 62 at, 268. For example, some causes of developmental disabilities after child birth include childhood accidents, drug and toxic substance poisoning through ingestion, delivery of very large or very small infants, metabolic disorders, malnutrition, RH blood disease, and intrauterine and other infectious diseases including rubella, cytomegalovirus infection, toxoplasmosis, syphilis, herpes, and enterovirus infections. Alta California Regional Ctr., *supra* note 68.

70. See BUCHANAN ET AL., *supra* note 62, at 266–267 (explaining that there is no evidence that a loss of support for disabled persons would result if the disabled population decreased in size).

ourselves.”<sup>71</sup> As a result, support for those “less fortunate” individuals could be reduced.

Again, the persuasiveness of this objection is impossible to evaluate without empirical evidence to support its key premises. There are examples of cases in which an increased emphasis on individual responsibility has led to decreased support (such as smokers being charged more for health insurance than non-smokers) and vice versa (such as support for treatment of alcohol abuse increasing as alcoholism became recognized as a disease rather than a bad habit).<sup>72</sup> Even so, our current system of disability accommodation does not differentiate between those whose disabilities are a result of the natural lottery and those whose disabilities are a result of their own risky decisions.<sup>73</sup> It is unclear whether this precedent would change if the Strong Claim or similar claims were to be more widely accepted.

#### IV. CONCLUSION

This article considered three important disability-based objections to the Strong Claim or similar positions, and there are multiple grounds on which to question the persuasiveness of each of these objections. Certainly, some readers will find these responses unconvincing. It is therefore worthwhile to consider where this analysis stands if the responses to these three objections fail. First, assume that the use of RGTs to prevent disability in future children sends a negative message to those who live with disability. Second, assume that the Strong Claim advocates parental attitudes that are morally problematic. Finally, assume that support for those living with disabilities would be diminished as a result of the widespread use of RGTs. These objections fail to prove conclusively that the Strong Claim is misguided or that potential parents cannot have a moral duty to use RGTs to reduce the likelihood that their future children will have a serious disability.

If sound, these three ethical arguments would have to be balanced against other relevant ethical arguments to determine whether the Strong Claim is morally defensible. It would be necessary to take all of these ethical considerations into account and to make a judgment about which considerations are the most important. The objections of the disability rights critique would weigh heavily in this judgment. But are they important enough to outweigh the moral arguments in favor of the Strong Claim?

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71. MICHAEL J. SANDEL, *THE CASE AGAINST PERFECTION: ETHICS IN THE AGE OF GENETIC ENGINEERING* 89 (2007).

72. See generally Meredith Minkler, *Personal Responsibility for Health? A Review of the Arguments and the Evidence at Century's End*, 26 *HEALTH EDUC. & BEHAV.* 121, 128–31 (1999).

73. See Tom Shakespeare, *Choices and Rights: Eugenics, Genetics and Disability Equality*, 13 *DISABILITY & SOC'Y* 665, 678–79 (1998).

Several of these arguments were previously discussed in this article:<sup>74</sup> acting in accordance with the Strong Claim may be a way of promoting the well-being of future children, may be required by the special responsibilities generated by the nature of the parent-child relationship, and may be in line with the imperative to fulfill other parental duties. To evaluate the defensibility of the Strong Claim, a judgment about which set of ethical considerations is more important must be made.

The ethical considerations that support the Strong Claim are more important than those that undermine it. The value of preventing a future child from having limited opportunities to pursue a good life and the moral obligation to protect a child from vulnerability seem to be weightier factors in the evaluation process than the value of not sending negative messages to those living with disability, the importance of appropriate parental attitudes, and the benefit of avoiding a possible reduction in support for disability accommodation. The former are more important than the latter for potential parents making reproductive decisions because it is not only permitted but expected that a parent be partial to the interests of their children. In other words, it is appropriate for a potential parent to consider the effects of a choice for her future child first and for other individuals second. This ranking of interests is reflected in the Strong Claim.

Making reproductive decisions consistent with the Strong Claim is not always easy for potential parents. Nor would widespread acceptance of the Strong Claim or similar claims be without negative consequences. Nonetheless, this article demonstrates that the Strong Claim is morally defensible despite disability-based arguments to the contrary.

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74. See notes 23-30 and accompanying text.