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Manuscript title: Disability Advocacy and Reproductive Choice: Engaging with the Expressivist Objection

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Abstract

This professional issues paper outlines the experience and value of engagement with disability advocates, philosophy scholars and bioethicists for spirited debate of issues such as modern eugenics, the expressivist objection and reproductive choice. This process for one group of individuals, undoubtedly prompted deeper examination and questioning of some long held personal and professional views, for all participants. For this author, engagement in the “Disability Rights – Genetic Counseling Interest Group” over a full year resulted in several positive changes in genetic counselling practice as well as the development of meaningful, robust philosophical defence of the dual roles in genetic counseling; advocacy for those with disabilities, and facilitation of a full range of reproductive choices.

Many published papers present commentary on the supposed contradiction of the genetic counselor's roles as an advocate for individuals with genetic conditions and as a facilitator of prenatal tests, which enable couples to select against particular genetic conditions (e.g., Biesecker & Hambi, 2000; Madeo, Biesecker, Brasington, Erby & Peters, 2011; Parens & Asch, 2003; Patterson & Satz, 2002; Raz, 2005; Shakespeare, 1998).

Like many genetic counselors, I did not always feel confident enough in my grasp of philosophical logic to challenge ethical stances and statements that I intuitively registered as inappropriate, or to defend prenatal genetic testing optimally. I occasionally had moments of self-doubt about the social impact of my profession, but I was able to shrug off these doubts with the very next clinical encounter that demonstrated how much individuals and couples value the new choices afforded to them by modern medical genetics. Prompted by a desire to genuinely reflect upon personal beliefs and moral values in the context of my chosen profession, I completed a program of study in ethics. As anticipated, it provided the opportunity to gain a deeper understanding of some of the contentious issues that underpin the alleged polarity between modern genetic counseling service provision and disability advocacy.

Early in that period of academic activity, I was directly confronted by a philosophy scholar who claimed that the role of genetic counseling is merely the "ethical mediation of eugenic futures," and that "genetic counseling is a profession deeply committed to shaping the decisions of patients" (Turnbull, 2000). Naturally, I bristled defensively and asked about his personal experience of genetic counseling, determined to understand how he had come to this appraisal. As it transpired, he had never had contact with a genetic counselor, but had

published his paper, which stated these assertions on the basis of journal articles (mostly from the disciplines of sociology and bioethics) and discussions he had with others whilst employed as a disability advocate in a government department. I argued that his stance was based on a fear of the unknown, rather than an understanding of the current goals, scope and ethics of professional genetic counseling. We came to an agreement that it would be mutually beneficial to start a “Disability Rights – Genetic Counseling Interest Group” that would regularly debate these issues, and complement our academic endeavors. The meetings were attended by students of philosophy and ethics, social workers (one, the mother of a son with Down syndrome), ethicists (with medical and theological training), a student with a disabling condition, and another genetic counselor.

The disability activist argument, known as the “expressivist objection” (Edwards, 2004), presented by the scholar, asserts that prenatal screening and diagnosis of conditions associated with a disability, and subsequent selective termination of pregnancy, are ethically unacceptable. The basis of the claim is that the screening approach, which offers termination of pregnancy as the main objective, expresses an intolerant and discriminating attitude towards particular disabling traits and, by logical extension, towards individuals with such traits. And, as it actively seeks to reduce the number of people with such traits, it is essentially the same as eugenics programs employed by the Nazi regime. Supporters of prenatal screening programs argue that these services offer couples the best opportunity to maximize their chance of delivering a healthy baby and, unlike Nazi eugenics programs, they involve respect for the individual’s autonomous choice and require informed consent.

The expressivist objection is a contentious stance, which has been extensively debated in peer reviewed journals, and is certainly not one that is endorsed by all disability activists,

individuals with disabilities, or parents of children with disabilities (Edwards, 2004; Holm, 2008). Some claim that these views are commonly held but empirical evidence is lacking. In fact, Tom Shakespeare, an individual who manages the physical challenges of achondroplasia, and is an academic sociologist in disability advocacy and bioethics, admits to being skeptical about the expressivist argument; but he agrees that it has been useful because it has forced public debate on the issue of negative portrayal of the disabled and disabilities (Shakespeare, 2008).

As a prenatal genetic counselor, I recognized that participation in a “Disability Rights – Genetic Counseling Interest Group” debate was a great opportunity to engage in ethical reflection on why and how we offer such prenatal services. This paper gives a brief overview of some personally defining exchanges from these very spirited debates.

I noted that we cannot claim to offer prenatal screening and testing for Down syndrome on the basis that it is usually a severe disability, which is incompatible with a reasonable quality of life. Historically, these services began because the technological capabilities (karyotyping and amniocentesis) became possible in an era when much higher morbidity and mortality were associated with the condition, and there was a general lack of social support for disability of any kind. However, despite much improvement in supportive services for individuals who have Down syndrome, and continual increases in quality of life, the demand for this screening remains high. Others argued that increasing social demand for these services is due to the persistent use of over-generalized, negative stereotypes, and the language of “tragedy and catastrophe” to describe the experience of life with Down syndrome (Clapton, 2003). This propagation of negative stereotype is said to be combined with pervasive messages from the medical model that imply a social responsibility to avoid

burdening the public health system, when the birth of a child with special needs can be prevented. I found these assertions difficult to counter, so acknowledged that, while there is some evidence for such claims, the psychosocial model advocated by genetic counselors seeks to actively change this trend, and I redoubled my efforts to ensure optimal language and balanced presentation of such issues. I also continue to stress this approach in student education.

I noted that it is not inappropriate to strongly desire to have the healthiest offspring possible, and one does not hear a similar objection in response to campaigns that advise women of the importance of folic acid supplementation to reduce the incidence of neural tube defects. Debate ultimately clarified that the main sticking point was the issue of termination of pregnancy in response to the diagnosis of particular conditions, rather than the actual reduction of the number of people with those conditions. Revelation of that viewpoint prompted an exploration of whether this stance is due to a fundamental objection to abortion, or to the belief that the fetus, in this case, represents a “type” of person directly targeted by an act of violence. The latter argument relies on acceptance of the belief that the fetus is the moral equivalent of a future person, which is a concept that has been intensely debated within philosophy literature, and will not be explored in this paper. That argument also suggests the expressivist objection is based on a premise that disability is identity constituting; that is, to make a concerted effort to seek out and eliminate “their type” in this manner, is to act in a demeaning and oppressive manner towards all members of this minority group.

I noted that disability advocacy groups, for some time, have promoted avoidance of the use of labels such as “Down syndrome child” or “cystic fibrosis sufferer” on the basis that the genetic condition or disability is just one small part of identity rather than identity constituting, and therefore it does not deserve disproportionate attention. I noted that, in

agreement with this sentiment, genetic counselors do not use such labels. Therefore, to insist that genetic conditions are identity constituting seemed to represent a contradictory and retrograde step for disability advocacy.

Others argued the message of prenatal screening programs is that the targeted “types” of people have lives that are not worth living. From my clinical experience, I suggested the situation is more accurately understood as “some individuals, in certain social contexts, will have lives that are much more difficult than they should be, with fewer regular options, and their families will also experience a degree of hardship as a result.” That is, as opposed to lives “not worth living,” they are lives that are “harder to live well,” and they may involve a degree of dependency that will socially isolate and financially penalize their primary care givers, unless the latter have access to extraordinary resources.

The family “quality of life” is an important contextual issue to consider (Gottlieb, 2002).

Throughout my career, I have regularly met inspirational families who have selflessly adapted their lives and priorities to maximize the support and wellbeing of a family member who is severely disabled. Some couples have had two or three severely disabled offspring in their family, particularly before the advent of prenatal testing options for severe conditions such as mitochondrial disorders and inborn errors of metabolism. One couple I counseled had four children, three of whom had differing genetic conditions: one severely physically disabled, one had cystic fibrosis and another had a condition that is associated with mild to moderate intellectual disability and some dysmorphic features. This family had a very strong religious faith as well as practical support from their extended family and parishioners. They appeared to be mutually supportive and completely accepting of “God’s plan for them,” as they expressed it; thus they projected a very balanced and positive attitude.

Unfortunately, I have also met women who came to clinic and talked about the strain of their dedication to caring for disabled offspring, and the challenges this strain imposed on their relationships with their partners. Sometimes, it led to separation, thus increasing the hardship and isolation for the woman. Similar to the nuclear family, the extended family may well be a myth for many, or relatives may be geographically removed, and villages no longer raise children. Clearly, families have very different measures of material, social, physical and psychological personal strengths and resources. The quality and amount of available resources impact family quality of life and ability to cope well with the challenges associated with disability in the family, especially if unsupported by external agencies.

I noted my experiences of counseling individuals, who have some type of disability or genetic disorder, who indicate a clear preference to avoid passing on the condition to offspring, and therefore seek to understand their reproductive options in order to increase personal control over the outcome. I acknowledged the women who have elected to continue a pregnancy after the diagnosis of Down syndrome, as a reflective moral decision, which was made feasible because they felt secure in their access to support and personal resources. I noted the many parents who clearly love, value and support their existing child with a serious chronic condition or disability, but who express a strong desire that their future children be unaffected by the same condition. As a result of my academic endeavors in philosophy, I developed confidence in defending these co-existing attitudes as ethically coherent, as have other bioethicists and researchers (e.g., Holm, 2008; Raz, 2005). Ultimately, we could all agree that it is the much wider social and political context that is most influential in personal attitudes towards disability.

So, thanks to the serendipitous challenge of a philosophy scholar, I was prompted to academically explore and defend principles and beliefs that I had not really examined adequately before. I wrote a Masters paper on the ethics of abortion, and then went on to undertake my PhD in bioethics. I now feel very confident in my ability to present compelling arguments for the ethical support of prenatal screening, genetic testing and elective termination of pregnancy, as coherent with advocacy for individuals with disabilities. I also feel more competent in my teaching and prenatal genetic counseling practice. As has been long recognized, engagement with individuals with disabilities, particularly those who expound the expressivist objection, as well as families who support individuals with disabilities, is vital for mutual understanding.

Madeo et al. (Madeo, Biesecker, Brasington, Erby, & Peters 2011) make several suggestions, such as programs of engagement with individuals and support agencies, aimed at improving relationships and mutual understanding. Many genetic counseling Masters programs have encouraged opportunities for such engagement for some time now, but we must become rigorous in evaluating and reporting the effectiveness of a whole variety of strategies so we may benefit from each other's experiences.

The most recent revision of Masters Program Accreditation Guidelines in Australia includes the requirement for 26 days of placement during the first year in settings outside of clinical genetics observation, that is, "community or health settings that provide students with insight into living with an inherited condition" (Human Genetics Society of Australasia [HGSA] 2010). This year in the Masters program that I convene at Griffith University, we have piloted a Community Volunteer – Student Engagement project that aims to help students gain deeper insight into the ways individuals and families manage and surmount the challenges (if

they perceive any) of a specific genetic condition. My colleagues and I anticipate this project will develop students' skills in presenting a balanced appraisal of quality of life issues associated with genetic conditions to consultands in the future. Preliminary feedback from both volunteers and students suggests this has been a well-received project with meaningful exchanges taking place, and no reported adverse outcomes thus far.

I have noted before that some misunderstanding, on both sides, is inevitable if we do not engage in clear communication to elucidate stakeholder perspectives (Peterson, 2008). Evidently, it is time to preferentially focus on positive strategies, aimed at mutual understanding and improved genetic counseling practice, which will work towards a better relationship between genetic counselors and disability advocates, rather than continue to highlight our profession's historical inconsistencies.

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