

NDSC POSITION STATEMENT ON PRENATAL TESTING AND SCREENING

(Editor's note: We reproduce this article with thanks "Down syndrome News", the journal of the National Down Syndrome Congress of America. It was also reproduced in Down's Voice, DSA of Victoria Vol. 17 No.1 Autumn 1995. The DSA (NSW) has never made a position statement on this subject and we would be glad to hear your views.)

There are concrete positions which disability rights groups along with other progressive groups can take to combat the current eugenics movement. These positions, which in no way involve the movement in the debate over whether a woman should have a legal right to abortion, were originally developed and proposed by Lisa Blumberg in the Disability Rag & Resource (Jan - Feb. 1994) and reprinted in the DSN (Vol 17, No.7)

Based upon those proposals, the NDSC Board of Directors has adopted the following position statement:

WHAT ARE FAMILIES' RIGHTS CONCERNING PRENATAL TESTING?

1. The decision whether to have prenatal tests must be solely that of the pregnant woman regardless of the woman's age, reproductive history or disability status.
2. All expectant parents should be informed as to the purpose of the different available prenatal tests as well as given information on the risks, limitations and expense of the tests, the manner in which these tests will be performed, and when during the gestation

period the results will be available. Consent and refusal forms must state that a decision to forego prenatal tests will not subject either the parents of the future child to loss of any medical care, insurance, legal benefits or community services that they would otherwise be entitled to. Legislation should be drafted as appropriate.

3. The results of all prenatal tests must be strictly confidential and may only be released to a third party with the parents' consent.
4. All women regardless of age, reproductive history or disability status must be given the absolute right to continue a

pregnancy after prenatal diagnosis. Legislation should be drafted as appropriate.

WHAT DO FAMILIES NEED TO MAKE INFORMED CHOICES?

- I. Disability groups should prepare packets of up to date information to be offered to all parents who learn that their fetus has a disabling condition. These packets should contain:
 - A. Information that seeks to dispel common misconceptions about disability and present disability from the perspective of a person with a disability;
 - B. Information on community based services for children with disabilities and their families as well as on financial assistance programs;
 - C. Materials on special needs adoption; and

D. A summary of major laws protecting the civil rights person with disabilities. People with disabilities and parents of people with disabilities should be available to talk to future parents.

- II. All medical students should be required to take at least one course in political and social issues of disability and all practising physicians should be required to take such a course as part of their continuing education requirements. All genetic counsellors, as part of their specialised training, must participate in an activity that will give them contact with persons with disabilities in non medical settings.

III. Family strengthening initiatives such as parental leave, part time and flexitime work, expanded child care alternatives, comprehensive health care programs and programs assisting low income families must be supported. Parenting a child with

a disability will become a more viable option for more people if society provided more supports for parents in general.

HOW SHOULD SOCIETY ADDRESS THE ISSUE OF PRENATAL TESTING AND EUGENICS?

1. Laws regulating abortion should be disability neutral.
2. Non pejorative, people first language should always be used when referring to persons and potential persons with disabilities. The term "defective fetus" is unacceptable.
3. Wrongful life suits are inherently discriminatory against persons with disabilities and should be prohibited. Wrongful births should only be permitted with children who are disabled if they are permitted with children who are nondisabled