



...what about 'the right to an open future'?

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The return of individual research findings in paediatric genetic research

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they already have the condition.²⁷ ²⁸ Carrier status may be interpreted as having an effect on their child's health. On a more theoretical level, children should have a right to an open future,²⁹ to decide on the information they want to know about themselves when they are ready to do so, and be shielded from too much curiosity from their parents' side. We believe, based on these data, that allowing parents full access to all genetic data of their children, possibly out of respect for parental autonomy, is not in the best interest of the children in question and should be prohibited.

FOR YOUR INTEREST? THE ETHICAL ACCEPTABILITY OF USING NON-INVASIVE PRENATAL TESTING TO TEST 'PURELY FOR INFORMATION'

ZUZANA DEANS, ANGUS J. CLARKE AND AINSLEY J. NEWSON

access to genetic counsellors).²⁰ The justice of offering NIPT for information, particularly if an offer of testing is made in the context of a screening programme, also raises issues around the responsibility of health professionals (such as genetic counsellors) to help ensure that any screening programs incorporating NIPT target serious conditions and do not impinge on a child's right to an open future.

Neonatale screening: nieuwe aanbevelingen

Screening for untreatable conditions: an ongoing debate

A growing number of voices in the scientific community and in patient organisations are calling for the inclusion of certain untreatable conditions in the neonatal screening programme. Other advantages, beyond clear health benefits, ought to be considered. Some of these may benefit the child, particularly shortening of the diagnostic process and adjustment of family life to deal with the consequences of the disease. Parents may also benefit from screening for a condition for which there is no effective treatment. If a child has such a condition, this knowledge may provide parents with information for making future reproductive choices. There are also disadvantages. The child's right to an open future is harmed. Furthermore, such knowledge may cast a shadow over the newborn's early life. As it is not self-evident that screening for untreatable conditions is in the best interest of the child, more extensive counselling would be necessary. This would place severe burdens on the current informed consent procedure.

Set up

- Right to an open future
- Application to genomic testing
- Useful concept in this context?

Right to an open future (ROF)

- Feinberg (1980)
 - A/C-rights: welfare rights eg health, bodily integrity etc.
 - A-rights: liberty rights eg right to vote, found a family etc.
 - C-rights:
 - dependency rights eg protection against abuse and neglect
 - 'rights in trust': ensure that the adult can later exercise A-rights (ROF)

Right to an open future (ROF)

- Context Feinberg's argument: Wisconsin vs Yoder
- Criticism: problems of maximizing interpretation
- Alternative: reasonable range of meaningful life choices.
- Preconditions of autonomy:
 - capacities
 - options

Genetic Dilemmas and the Child's Right to an Open Future

by Dena S. Davis

Dena S. Davis, "Genetic Dilemmas and the Child's Right to an Open Future," *Hastings Center Report* 27, no. 2 (1997): 7-15.

March-April 1997

Genetic dilemmas

- Selective reproduction
 - Deaf parents wanting a deaf child. Davis:
 - Parental practices that close exits virtually forever are insufficiently attentive to the child as end in herself. By closing off the child's right to an open future, they define the child as an entity who exists to fulfill parental hopes and dreams, not her own.
 - Savulescu & Kahane (Bioethics 2009): select future children with the aim of intentionally *promoting* their expected autonomy.

Genetic dilemmas

- Genetic testing
 - Parents asking to test a child for adult-onset disorder such as HD. Davis →

The notion of the child's right to an open future can help in confronting the question of whether to test children for adult-onset genetic diseases, for example Huntington disease.²⁹ It is well known that the vast majority of adults at risk for Huntington disease choose not to be tested. However, it is not uncommon for parents to request that their children be tested; their goals may be to set their minds at rest, to plan for the future, and so on. On one account, parental authority to make medical decisions suggests that clinicians should accede to these requests (after proper counseling about possible risks). A better account, in my opinion, protects the child's right to an open future by preserving into adulthood his own choice to decide whether his life is better lived with that knowledge or without.³⁰

Pred testing children for ad-onset dis

- AAP 2001:
 - “testing in childhood inappropriately eliminates future autonomous choice. (...) unless benefit to the child, pediats should decline requests until child has capacity to make the choice”
- ESHG 2009:
 - “(...) acceptable only if preventive actions can be initiated before adulthood. Otherwise (...) deferred until person has maturity and competence”

Pred testing children for ad-onset dis

- AAP & ACMG 2013:
 - “generally should be deferred (...). Exception might be made for families for whom diagnostic uncertainty poses a significant psychosocial burden, particularly when adolescent and parents concur in their interest (...).”
- ASHG 2015:
 - “deferring until adulthood allows children opportunity to make their own decisions.”
 - “(...) parents should be encouraged to defer (...).”
 - “can be justified when requested after informed deliberations and not clearly inconsistent with welfare of child.”

Shift

- More experience and empirical data about impact (limited)
- NGS era opens up new contexts for debate about principles of genetic testing of children
 - Incidental findings of clinical NGS-based testing
 - Idem, pediatric research
 - Potential for NGS-based screening
- Bredenoord et al (2014): may go hand in hand with shift from individual rights to family-based approach

Criticism

- Bredenoord et al 2013/2014:
 - “not clear why the ‘right to an open future’ principle should be abandoned”
- Clarke 2014:
 - “commitment to preserve child’s right to an open future.”
 - “while suggesting that deferral of testing is to be preferred, these [AAP/ACMG] guidelines are disappointingly open to professional weakness; they fail to challenge the practitioner willing to test a young child at risk of HD and could undermine attempts to maintain high ethical standards in genetic counselling practice.”

ROF: what does it protect here?

- Deontological interpretation
 - Autonomous choices
 - Maximization problem
 - Possible conflict between future autonomy rights and present beneficence
- Consequentialist interpretation
 - Interests: not forced to live with info about I-o disorders that most adults at risk choose not to be tested for
 - Opportunity to make one's own choices when mature enough to do so is one relevant consideration in a best interests approach (Kopelman 2007)

Parental & professional responsibility

- Parents: responsibility to decide in the interest of the child. Parents usually in best position for this.
- Professionals: should normally respect decisions parents make on behalf of their children, including in situations where the child's interest is unclear (if based on well-informed deliberation).
- In cases where professionals have strong grounds for thinking that parental choices are harmful, they do have a responsibility to protect the child.

IF of pediatric WES

- Late onset disorder, actionable in adulthood
 - Unlike in affected families (where ROF supports postponing to adulthood) child is not known to be at risk. In the interest of the child (+ possibly of family members) info should not be lost. No valid ROF-claim against disclosure.
- Late onset, non-actionable
 - If ROF opposes testing, it also opposes disclosure (Bredenoord 2014: impact is the same)
 - But as the info is available, parents may want to know.
- Carrier status recessive disorder
 - ROF should not oppose opt-in.

Neonatal screening

- Genome scan at birth?
 - Human Genetics Cttee (UK) “Profiling the newborn” 2005
 - Child unable to consent
 - As long as most adults do not want to have their full genome analyzed, valid ROF claim against doing so in children
 - ROF not only challenged by revealing serious untreatable late onset disorders, but possibly also by mild conditions that in most individuals would not have led to diagnosis.

Prenatal screening

- The informational interests of the future child have only become an issue with the recent expansion of the scope of genetic prenatal tests.
 - Same ROF arguments as re neonatal genome scanning
 - Interest of the future child in not being sent into the world with his/her full genome analyzed limits appeals to ‘reproductive autonomy’
 - ESHG/ASHG recommendations (2015): prenatal screening not to be expanded beyond serious congenital and childhood disorders

ROF: what does it add?

- Millum 2015:
 - Talk of a right to an open future [...] ends up being unhelpful: it is likely to obscure the detailed arguments that must be provided to defend keeping a child's future open in some particular respect or providing her with particular skills and opportunities.
- ROF does not add anything to a comprehensive analysis of the child's best interests as positively or negatively affected by genetic testing
- However, the argument may still be useful by reminding us that such a comprehensive analysis should also take account of how the information in question would impact on the life and options for choice of the future adult or adolescent.