Life Story: The right to know one’s origins

Discovering and developing the self is important for all human beings. Self-identity is a process of continuous creation and reshaping throughout the lifespan. One’s personal identity is shaped by one’s country of origin, culture, race, language and the like. In building one’s own identity it is common for individuals to ask questions such as “Who am I?” and “Where do I come from?” Such questions are personal questions, but in recent years some people have also asked these questions in a very public manner, with the attempts to generate the answers being made into television programmes. For example, recent television programmes in the United Kingdom on BBC One and in Australia on SBS entitled *Who Do You Think You Are?* have reported on the experiences of celebrities who trace their family trees and uncover family histories.

However, for some individuals creating their own life story, starting with the “Who am I?” question may not be so easy. For some individuals it will be necessary to integrate multiple identities. Individuals who are adopted are one group for whom the task of identity formation may have many challenges. For individuals in this group there comes a point when one recognises that one is associated with two families. Over time these individuals must build a dual identity. In doing so, learning about one’s past and one’s origins will be an important step. For individuals who are international adoptees, such a recognition and subsequent search for information about one’s biological parents may be especially important.

There is also another group for whom the “Who am I?” question is a very salient question. This is the group of individuals who have been conceived through assisted reproductive techniques. This group, who are often referred to as “donor-conceived children”, may at some point in their lives also wish to have information about their genetic origins.

Thus, one aspect of the search for identity for individuals in both of these groups is the search for their genetic origin. The rights to disclosure of information about genetic origin are enshrined in international instruments and agreements and are enacted in international and, increasingly, domestic legislation. The main international instruments that are central to a discussion of the rights to information about one’s genetic origins are the following:

- Convention on the Rights of Persons with Disabilities (United Nations, 2006),
- European Convention on Human Rights (The Council of Europe, 1948),
- The Hague Convention on the Protection of Children and Co-operation in Respect of Intercountry Adoption (The Hague Conference on Private International Law, 1993), and

For example, with respect to the Convention on the Rights of the Child, Article 7.1 acknowledges the right of children to know their parents and be brought up by them, and for adopted children it guarantees the right to know their origins. Article 8 of the European Convention on Human Rights secures the right to respect for private and family life. The
Convention on the Rights of Persons with Disabilities protects and promotes the human rights of people with disabilities. Because amongst other areas the Convention covers equality and non-discrimination, it is applicable to the right to know one’s origins.

With respect to the Convention on the Rights of the Child and case law of the European Court on Human Rights there are a number of differences. Indeed, Besson (2007, p. 137) has stated that the Convention on the Rights of the Child’s essential focus on the rights of the child can be contrasted with the European Court of Human Rights’ case law that offers a “more nuanced balancing” of the competing rights of the child and parents. Tulkens (2007), a Judge at the European Court of Human Rights, has reported on some of the cases the European Court of Human Rights related to Article 8, indicating that: “in some recent judgments the Court has recognised the right of children to know their origins, the identity of their parents and the circumstances of their birth”. Tulkens (2007) goes on to state:

… in this currently sensitive area in which developments are obviously speeding up as a result of the growth of biotechnology, the Court is increasingly confronted with conflicts between fundamental rights: the child’s right to know his or her parentage versus the right of the mother, for example, to preserve her anonymity or her privacy or the father’s right not to submit to DNA tests.

Furthermore, in many countries such as the United Kingdom and in several states of Australia there is legislation in place that enshrines the right to certain information about one’s genetic origins, and that provides protections for donor-conceived children related to requesting and accessing such information, as well as providing protections for donors.

However, issues such as age for disclosure, requirements for counselling, and the operation of confidential registers vary greatly from country to country or in different states within countries (e.g., Australia).

In recent years some important research has been undertaken regarding issues related to children’s right to know their genetic origins. The majority of this research relates to donor-conceived children rather than to adopted children. For example, Petersen (2006) investigated the rights of donor-conceived children to know the identity of their donor, and more recently Blyth and Frith (2009) and Blauwhoff (2009) have reported research of the legal developments in a number of European countries (e.g., Germany, the Netherlands) related to seeking information about one’s origins. Both Blyth and Frith and Blauwhoff provide comparisons identifying the similarities and differences between the United Nations Children’s Rights Convention and case law of the European Court on Human Rights. Similar to Besson (see above), both groups of authors point to the issue of conflicting rights; specifically, the rights of individuals to know their biological parents compared with the parent’s rights to privacy, especially as dealt with in the European Court.

Such research and writing is helpful in clarifying the legal issues associated with the right to know one’s origins; however, it says very little about the ethical, personal and social aspects of the right to know one’s origins. In this regard, I argue that future research, which investigates both the legal and the personal and social elements of the search for identity, will be important. Analytical examinations from multiple perspectives of the benefits and risks of the right to know one’s origins are likely to have useful implications for policies and guidelines for professionals and policy-makers and for the improvement of information and services for adoptees, donor-conceived children, adoptive, and biological parents.

In this Issue
The right to education is rightly sought by many individuals throughout the world. However, an understanding of exactly what this right means and how it should be
articulated in legislation and policy is much debated and demonstrated in diverse ways in different countries and jurisdictions. Seema Shah examines how Canada has implemented this right for students with disabilities. The article focuses attention on students with epilepsy and examines how Canada’s laws align with international laws on this topic. By examining three types of barriers to education faced by these students, Shah argues that students with epilepsy will not be protected by Canada’s Charter of Rights and Freedoms and the Ontario Human Rights Code.

In the second article, Yuriko Kishida and Coral Kemp report a study that established the ability of early childhood practitioners to use the Individual Child Engagement Record – Revised. This observation tool can be used as a measure of children’s engagement and interactions in inclusive education settings. The article highlights the importance of training to obtain inter-observer agreement on measures such as the Individual Child Engagement Record – Revised.

The third article by Anette Sandberg, Anne Lillvist, Lilly Eriksson, Eva Björck-Åkesson, and Mats Granlund examines the definitions given by preschool staff of the construct “young children in need of special support”. Set in Sweden, the authors found that participants either had a child or organisational perspective. According to the authors, there are particular factors (e.g., child characteristics) that influence these perspectives, and many of these perspectives in turn may influence the services provided to these children.

Marloes Koster, Sip Jan Pijl, Han Nakken, and Els Van Houten examine the social participation of students in the first three years of primary school in the Netherlands. The study compared the social participation of those with and without special needs. The results indicated some of the negative outcomes related to social participation of students with special needs. The authors provide reasons for the findings that suggest inclusive education, which is thought to address the lack of social participation of students with disabilities, may not be as effective in this respect as previously thought.

A very particular form of social participation is explored in the final article in this issue. Gillian King, Mary Law, Patricia Hurley, Theresa Petrenchik, and Heidi Schwellnus examine out-of-school recreation and leisure activity participation of boys and girls with and without physical disabilities. This Canadian investigation highlighted both gender and age differences with respect to participation in activities. The authors note a number of the differences related to active physical or social activities, or to activities that the students undertook with others.

References


Editorial


Christa van Kraayenoord

*School of Education, The University of Queensland, Brisbane, Australia*