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Caring for Children with an Intersex Variation

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Caring for Children with an Intersex Variation

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Introduction

This chapter builds on the anti-bias approach espoused in this edition. It is grounded in the Convention on the Rights of the Child (CRC) (see: <https://www.humanrights.gov.au/our-work/childrens-rights/convention-rights-child>). It also draws on an understanding of children's lifeworlds (Clark and Moss, 2001) and how children's knowledge about their bodies, sex, gender and sexuality reflects their intersectional, layered and situated lived experience (Robinson and Diaz, 2016). This chapter focuses on how to best meet the needs of **children with an intersex variation** who may experience 'normalizing' interventions (Carpenter, 2018a) that violate the CRC. These interventions mostly occur between the ages of 0-18, a period where education plays a pivotal role in identity formation (Carpenter and Zavros-Orr, 2019; Jones, 2016). Notions of being, belonging and becoming (Department of Education, Employment and Workplace Relations (DEEWR), 2009) underpin early years as well as shape later years of education. Teachers, however, may not be aware of the lived experiences of children with an intersex variation that are also shaped by medical interventions and/or normative expectation about what it means to be 'male' or 'female' (Davis, 2013 and 2015; Karkazis, 2008). A focusing question for all

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teachers and leaders is: How can we create safe, supportive and caring learning spaces for children with an intersex variation?

What is intersex?

Intersex, an umbrella term, is recognised in law as reflected in the Sex Discrimination Amendment

(Sexual Orientation, Gender Identity and Intersex Status) Act 2013 (see:

<https://www.legislation.gov.au/Details/C2013A00098>). Understanding of this term is important for teacher education, professional development, curriculum development, teaching and meeting of professional standards, policy, guidelines and administrative practices. Answering the question ‘what is intersex’ involves disrupting assumptions about bodies (Androgen Insensitivity Syndrome Support Group Australia, Intersex Trust Aotearoa New Zealand, Organisation Intersex International Australia et.al., 2017). It also means being mindful of ‘othering’ intersex people in ways that construct intersex as a third sex (Carpenter, 2018a). Here is a summary of what intersex means, that can inform, teaching, leadership, scholarship and reflective praxis:

Intersex refers to being born with genetic, chromosomal, hormonal or physical sex characteristics that do not fit normative notions of ‘male’ or ‘female’ bodies. These may be evident at birth or become evident at subsequent stages of life. Intersex (as a status of being) may be used by people with one of many intersex variations. Intersex is not a gender identity or sexual orientation. Individuals may use the term intersex, and some may not. Some might use other terms, such as the name of the variation (e.g. Turners, Swyers, Klinefelter etc.) or acronyms such as AIS, CAIS, PAIS or chromosomal type 46XY (female), 45,X/46,XY mosaicism, XXY, XXX or

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XYY. Intersex people may view their bodies as being male, female, both or non-binary. Intersex people may be, heterosexual, transsexual, bisexual, same-sex attracted or asexual.

There are about 40 known intersex variations. Whilst definitive data is hard to collect, it is estimated that up to 1.7% of children are born with an intersex variation (see: <https://ihra.org.au/16601/intersex-numbers/>). Intersex is a part of human biological diversity (and part of the natural world), and as such, terms such as ‘Disorders of Sexual Development’ (DSD) or as sometimes expressed ‘Differences in Sex Development’ reflect a process of othering that is stigmatizing and pathologizing.

A good starting point in deepening understanding of what intersex means is reading the Darlington Statement (see: <https://darlington.org.au/>) as it provides a community-focused human rights perspective. It advocates for a concerted endeavour to address biased societal and medical perspectives (Lee, Nordenström, Houk, et al., 2016) that can fail to consider the psycho-social effects of interventions on health, wellbeing and subsequently on education and employment. Hence the emergence of an international and national human rights movement in support of individuals with intersex variations. For some, there may be a need to access health care or medical support (see: <https://www.who.int/genomics/gender/en/index1.html>) and in some cases legal, social, emotional and learning support. This support must not be situated within a normative binary understanding of ‘male’ or ‘female’ (Butler, 2006; Colangelo, 2017) but differentiated to meet the needs of the individual. In education, this means reviewing personalized and pedagogical frameworks making sure that they are mindfully inclusive of intersex (Brömdal, Rasmussen, Sanjakdar, Allen, & Quinlivan, 2017).

Issues and experiences of children with an intersex variation

Children with an intersex variation are members of diverse families, from different ethnic and linguistic backgrounds and may be members of faith/religious communities. Published accounts of lived experience often reflect violations of the four guiding principles of CRC: their best interest; survival and development; voice on matters that affect them and; enjoyment of CRC without discrimination (see; <https://www.humanrights.gov.au/our-work/childrens-rights/about-childrens-rights>).

Jones (2018) explained that the lifelong health needs of children are, “located at the intersection between the fields of law, medicine and human rights” (p. 382). Richards and Wisdom (2019) identified ethical, medical, and legal issues underpinning the complex question of how to appropriately support the needs of intersex children. They highlight that “there is only one certainty with regard to the diverse needs of intersex children: there is a complete lack of consensus on what should or should not be done” (p. 91). Adults acting on children’s behalf must work from an ethic of care where there is significant effort to understand the issues and experiences of children with an intersex variation.

The 2016 Family Court case, Re: Carla highlights how heterosexist socio-cultural frameworks shaped the lived experience, health, and wellbeing of a child. Carla, a 5-year old had genital enhancement surgery, gender reassignment and was sterilised, drawing on biased medical data of cancer risks (see: <https://ihra.org.au/31036/re-carla-family-court/>). Richards and Wisdom (2019) in their analysis of this case argued that “whilst at times those intersex status have corresponding medical conditions that may (or may not) require clinical treatment, the status in and of itself is not a medical condition” (p. 79). A human rights approach is essential for meeting the needs of individuals with an intersex variation (Morgan, 2018b).

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A sociological study of 272 participants (Jones, Hart, Carpenter, Ansara, Leonard, & Lucke, 2016), illustrated the importance of understanding the lived experience of intersex people. The study found that most people with an intersex variation find out before they turned 18, with many experiencing medical interventions in the absence of personal informed consent and secrecy. Doctors argue that parents are entitled to consent, and consent is part of the process of such interventions, however, it is questionable whether this is always informed (Kelly and Smith 2017; Richards and Wisdom, 2019). Parents and families are often given biased information (Jones, 2017), but what is more concerning is that children are not given accurate age-appropriate information about their bodies and their intersex status/variation or are not told at all (Carpenter, 2018; Davis, 2013; Karkazis, 2008). The ongoing practice of withholding information and promoting of a code of secrecy fosters shame, depression and anxiety (Davis, 2013; Jones, 2017). My research (exploring web-based and published accounts of people with an intersex variation) has found that there is diversity, and sometimes tension about what it means to be intersex and being male or female. This may result in conflicted understandings of one's sex, gender and sexuality.

If we are reading or listening to people's accounts, we must acknowledge that each account is a personal truth and honour that. Learning to '**be**' in our bodies is an endeavour that begins at birth and that requires access to unbiased information and support. Those who have legal responsibility for a child's welfare have a duty of care, concerning the provision of this. Such support aligns with the underlying principles of an anti-bias approach for the development of healthy ways of being, belonging and becoming (DEEWR, 2009) and promote a healthy self-image, self-esteem and self-worth. Trauma can overwhelm a young person's ability to cope, cause feelings of helplessness, diminish their sense of self capabilities and may thwart their capacity to feel a full range of emotions (Wall, Higgins and Hunter,

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2016) often resulting in withdrawal from social contexts as a safety mechanism. Some children with an intersex variation may not become aware of this until later in life, either because it has not become manifest (e.g. until puberty) or because the information has been withheld from them. Some chromosomal variations are associated with other physical, learning needs and neurodiversity issues of which educators need to be aware.

Being an ally for children (people) with an intersex variation

As early as 2004, Butler critically examined the lived experiences of intersex people. Butler's work emphasizes the importance of critical thinking and questioning how psychoanalytic praxis informs the medical treatments provided to intersex people. This means there is a need to examine learnt assumptions about the performativity of sex, gender and sexuality and their interconnectedness. The learning for teachers and leaders is that we must be mindful of the pervasive bias in educational content and illustrates the importance of teaching and programs being informed by an anti-bias approach. This is important for making sure that all programs – 'do no harm'. Developing a broad understanding regarding intersex variations and associated needs is important for providing a safe, supportive and caring learning environment for children with an intersex variation. Education can play a key role in improving outcomes for children with an intersex variation.

Children with an intersex variation, like all children, need to be provided with safe spaces for physical, social, emotional, spiritual and academic development. Children express, impress and mirror through the 100 languages that reflect their life worlds (Edwards, Gandini, and Forman, 1998). Learning to be inclusive, calls for an un-learning and re-learning about bodies, their sexuality and gender identities

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(Brömdal, et al., 2017). Re-learning can be informed by the work of Robinson and Diaz (2016) thinking about the intersectional nature of their life worlds - family, community and identity. This can be informed by broader international, national and state frameworks for health and wellbeing. Embracing an intersectional perspective, teachers can take action by:

- Reading and affirming the Darlington Statement referred to earlier (see:
<https://darlington.org.au/>).
- Actively listening to children (without bias).
- Providing resources, both tangible and intangible that are inclusive of intersex people.
- Reviewing practices, policies and administrative regimes to ensure they are not stigmatising or discriminatory (Foreman, and Arthur-Kelly, 2017).
- Promoting bodily integrity, autonomy and body diversity irrespective of sex, gender or sexuality (Robinson and Diaz, 2016).
- Supporting a healthy understanding of bodies, and individual rights.
- Engaging with the lifeworld of the child (Clark, and Moss, 2001).
- Not pathologizing bodies, reinforcing sex stereotypes or heterosexist ideas.
- Collaborating with families and the intersex community in a manner inclusive of the physical, social, emotional, spiritual and intellectual developmental needs of these children (Rathus, 2016).
- Providing relevant and reliable information to children and their families (see:
<https://headtohealth.gov.au/supporting-yourself/support-for/intersex>).
- Accessing community support (*Intersex Peer Support Australia* (IPSA) <https://isupport.org.au/> and *Intersex Human Rights Australia* (ihra) <https://ihra.org.au/>) or professional development (see: <https://diversitywise.com.au/>)

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It is important to understand that the population of people with an intersex variation is not readily visible. This means when implementing any curriculum, such as the Australian Early Years Learning Framework (see: <https://docs.education.gov.au/documents/belonging-being-becoming-early-years-learning-framework-australia>), educators must consider the **impact** of the planned and unplanned, intentional and unintentional teaching. Here are three quality resources for building sensitivity to the lived experience of intersex people that can inform praxis:

- ABC episode of You Cannot Ask That – What is Intersex?
 - <https://ihra.org.au/35112/you-cant-ask-that/>
- Raising Rosie: Our Story of Parenting an Intersex Child by Eric and Stephanie Lohman
 - <https://ihra.org.au/23099/raising-rosie/>
- The TED talk by Kristina and Ori Turner – a parent and child talking about being intersex
 - https://www.ted.com/talks/kristina_turner_ori_turner_intersex_is_awesome

Respectful, responsive and reciprocal relationships can build a human rights informed praxis in keeping with the implementation of the Australian Governments health and wellbeing framework (see: <https://www.education.gov.au/national-safe-schools-framework-0>). In doing so, it is important to be actively listening to children and supporting their learning and leadership (Moss, 2001) on topics that matter to them. I am constantly inspired by children's views on diversity including bodies and identities, given they are naturally curious, often less judgemental and work from an ethic of care that is about seeking understanding.

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The mosaic approach (Clark, and Moss, 2001) can provide a method for engaging children's voices.

Another technique that has been specifically developed to listen to young children (designed for working specifically with communication impairments but more broadly applicable) is the Speech Participation and Activity in Children (SPAA-C) (McLeod, 2004). The SPAA-C was developed as a result of consultation with over 200 Australian speech pathologists and contains questions about the daily lives of children.

Age-appropriate stories about intersex children and adults who are leading successful lives should be provided to children. Intersex people have existed as part of society from the very beginning. Similarly, across the world, different communities have embraced and celebrated people with an intersex variation. Intersex Awareness Day draws attention to issues and promotes awareness and builds knowledge about what intersex means. Consider inviting someone to speak with you and your community. Having a conversation with members of the intersex community can be a first step to gaining insight and informing an anti-bias approach - moving our educative communities closer to being fully inclusive.

Putting an Anti-bias Approach into Practice

1. What is your understanding about sex, gender and sexuality (noting any bias that reflects heteronormative/heterosexist ideologies)?
2. What do you now understand about what it means to be intersex and where are the gaps in your understanding? What do you want to know more about?

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3. How can you engage in scholarship, leadership and pedagogical change for creating safe, supportive and caring environments that meet the needs of children with an intersex variation?

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