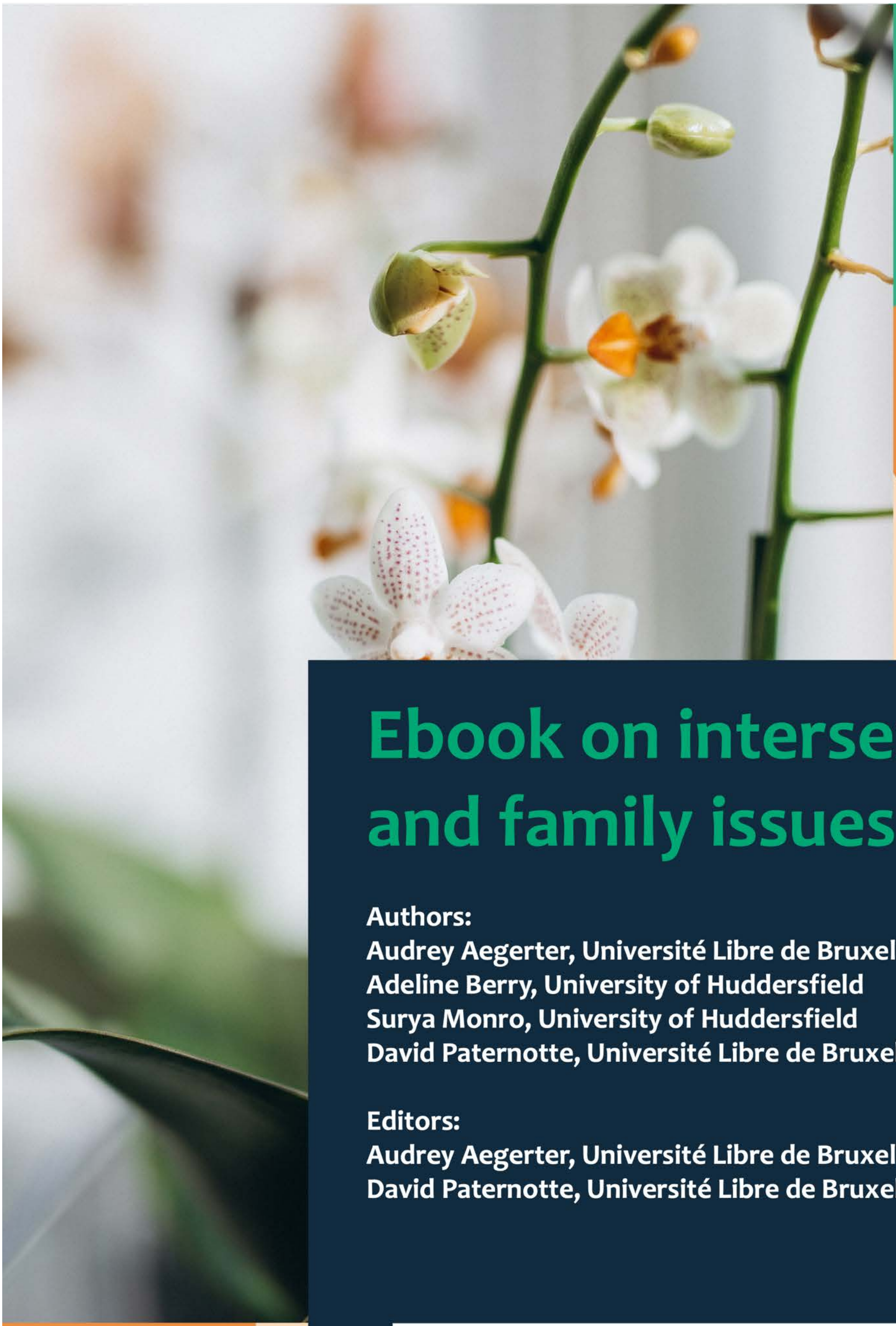

Ebook on intersex and family issues

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UAB Universitat Autònoma de Barcelona

Ebook on intersex & family issues

Edited by Audrey Aegerter & David Paternotte

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Introduction[1]

Audrey Aegerter & David Paternotte

Intersex people are born with a set of sex characteristics that do not fit the typical definition of male or female bodies. In a medical context, they are perceived as pathological and addressed as disorders despite, with few exceptions, posing no harm to the health of the intersex person. Since the 1950s, intersex children have routinely been subjected to non-consensual medical treatments, such as surgery, hormone therapy, and/or vaginal dilatations, to conform their bodies to social expectations. Today, these treatments are highly contested, both in the fields of social sciences and activism. Some go as far as to consider them as forms of torture and genital mutilation.

The effects of medical intervention on an intersex variation can impact a person throughout their life. While there is a growing body of literature opposing the medicalisation of intersex children, mainly in the fields of law, sociology, and psychology, there is little research done on the context of intersex and family issues. Families are the cornerstone in the life of an individual but families can be defined differently. Family is the environment in which a child grows up, but it is also the environment that an individual shares with relatives, their partner, and perhaps offspring. Families do not need to be genetically linked or through marriage; many people find support amongst 'chosen' or 'logical[2]' family. This eBook discusses ways in which intersex variations can influence the experience of family for intersex people in Europe.

All authors are part of the research project INIA, Intersex: New Interdisciplinary Approaches[3]. Funded by the European Commission between 2020 and 2024, INIA gathers academics and researchers from 7 higher education institutions in Europe: the University of Huddersfield, the University of Loughborough, the Université libre de Bruxelles, Dublin City University, the Universitat Autònoma de Barcelona, the Escuela Andaluza de Salud Pública and the Universität Zürich. Over 4.5 years, it has trained a cohort of early stage researchers on intersex issues and contributed significantly to the development of intersex studies in Europe.

This eBook is organised in four chapters. First, Surya Monro and Addy Berry sketch an overview of intersex life trajectories. Secondly, Addy Berry and Audrey Aegerter explore relationships between intersex people and their families, in particular parents and siblings. Thirdly, the authors examine relationships and families formed by intersex people over the course of their lives. Finally, Addy Berry discusses the challenges of ageing for intersex people.

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[1] This work was undertaken as part of INIA, Intersex – New Interdisciplinary Approaches' Innovative Training Network supported by a grant from the European Commission's Marie Skłodowska-Curie Actions program under grant number 859869. This report reflects only the views of the authors, and the agency is not responsible for any use that may be made of the information it contains.

[2] Maupin, A. (2017). *Logical family: A memoir*. Random House.

[3] INIA: Intersex – New Interdisciplinary Approaches. (n.d.). https://www.intersexnew.co.uk/

Chapter 1: Life trajectories[4]

Surya Monro & Addy Berry[5]

1. Introduction

Intersex and variations of sex characteristics[6] are always congenital (people are born with a variation of sex characteristic, although for some variations, these do not show up until later life or perhaps not at all). Intersex variations can originate from genetic, chromosomal, physical or hormonal variations or a combination of these factors. Environmental influences such as endocrine disruptors can play a role in some intersex differences[7]. The term 'Intersex' refers to people born with a combination of sex characteristics (chromosomal, gonadal and/or anatomical[8]) that do not fit the typical definitions of male or female[9]. The United Nations estimates that between 0.05% and 1.7% of infants are born with intersex traits[10]. Inclusion of some variations as intersex, i.e., hypospadias, are disputed by some medical professionals, hence some of the variation in figures[11].

The terms 'Disorders of Sex Development' was introduced in the Chicago Consensus Statement 2006[12] and subsequently this term, and the term 'differences of sex development', are often used in medical settings for people who are intersex and/or have Variations of Sex Characteristics. Many intersex people or people with Variations of Sex Characteristics reject the term 'Disorders of Sex Development' as unnecessarily pathologising[13].

Whilst a life course approach addresses a sequence of events enacted over time[14] (Elder et al., 2003), these events are socially contextualised and may not take place in any particular order. Therefore, whilst the sections of this chapter are in chronological format (prenatal, birth and postnatal period; childhood; transition to adulthood; adulthood; older age), particular events may happen at different times to those normatively expected amongst endo (a term for 'non-intersex') populations, or not at all.

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[4] Some material in this section of the ebook previously appeared in this report: Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). Intersex, Variations of Sex Characteristics, and DSD: The need for change. University of Huddersfield. http://eprints.hud.ac.uk/id/eprint/33535/

[5] We also acknowledge Daniela Crocetti, who contributed to writing the sections of the following report that Monro and Berry's chapter draws on. See Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F. & Travis, M. (2017). *op. cit.*

[6] Please note we use these terms interchangeably in this chapter.

[7] Oiiuk.org.

[8] Including hormone receptor variants.

[9] Lee, P., Houk, C., Ahmed, F. S., & Hughes, I. A. (2006). Consensus statement on management of intersex disorders. *Pediatrics*, *118*, 488–500.

[10] HCHR. (n.d.) *Fact sheet: Intersex*. https://unfe.org/system/unfe-65-Intersex_Factsheet_ENGLISH.pdf

[11] IHRA. (2019, September 16). *Intersex population figures.* https://ihra.org.au/16601/intersex-numbers/

[12] Hughes, I. A. et al. (2006). *Consensus statement on management of intersex disorders*. http://www.aissg.org/PDFs/Chicago-Consensus-Statement-06.pdf

[13] Davis, G. (2011). "DSD is a perfectly fine term": Reasserting medical authority through a shift in intersex terminology. In *Sociology of diagnosis* (Vol. 12, pp.155-182). Emerald Group Publishing Limited.

[14] Elder, G. H., Johnson, M. K., & Crosnoe, R. (2003). The emergence and development of life course theory. In: Jeylan T. Mortimer & Michael J. Shanahan (eds.). *Handbook of the life course*. Springer.

The chapter starts with a snapshot of some of the cultural forces affecting intersex people and their families before birth as well as later. We then move on to address the following: embryo selection and pre-birth interventions, birth, infancy-adolescence, adolescent-adulthood, middle adulthood, older adulthood.

2. Before birth

Cultural norms about gender/sex binarism and about normative bodies

Medical interventions concerning intersex bodies were made routine during the 1950s for people with bodily characteristics that were previously kept in the private realm and not routinely pathologised[15]. A wide range of interventions are now put in place regarding variations of sex characteristics[16]. Some of these interventions are life-saving and necessary, for example if a baby is born without the capacity to urinate or if hormone treatment is required (as in the case with some variations of Congenital Adrenal Hyperplasia (CAH)). However, most of the interventions currently taking place are not necessary for physical functioning and are done because of ideas about what is socially acceptable. The key issue is that variations of genitals, chromosomes, and hormones are seen as pathological – this is challenged by the intersex movement, an increasingly substantial scientific literature, human rights institutions, and some allied medical professionals.

Intersex and variations of sex characteristics occur naturally. Intersex people and those with variations of sex characteristics may need specialist healthcare, and we have found that getting access to appropriate healthcare is extremely important to intersex people[17]. This is the case when medical interventions are necessary for survival, where they are felt to be needed by children who are mature enough to make fully informed choices, or by adults with variations of sex characteristics who feel that they need medical interventions. However, this is not the same as framing an entire group of people as having a problem or suffering from pathological conditions. This leads us to ask why early irreversible interventions still take place in most countries, especially when the side effects are often very serious and harmful. There is a growing shift away from these interventions, which have been banned in several countries.

The ‘problems’ regarding intersex people are mostly to do with wider society, where rigid ideas about male and female bodies are very strong. Sometimes these ideas are due to tradition, although historically many societies included what we now call intersex people as

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[15] Fausto-Sterling, A. (2000). *Sexing the body*. Basic Books; Caffaratto, M.T. (1963) *L'ermafroditismo umano*, Minerva Medica; Foucault, M. (1980). *Herculine Barbin*, Pantheon Books; Dreger, A. D. (1998). *Hermaphrodites and the medical invention of sex*. Harvard University Press; Reis, E. (2009). *Bodies in doubt: An American history of intersex*, John Hopkins University Press; Karkazis, K. (2008). *Fixing sex: Intersex, medical authority, and lived experience*, Duke University Press.

[16] Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone research in paediatrics*, *85*(3), 158-180.

[17] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). Towards an agency-based model of intersex, variations of sex characteristics (VSC) and DSD/dsd health. *Culture, health and sexuality*, *23*(34), 500-515.

citizens[18] without finding a need to pathologise them. In some cases, rigid ideologies about sex and gender come from religion, but there is research to show that intersex can be seen as a gift, and accepted, within some spiritual traditions[19].

Some medical professionals, and others working in the intersex area, state that 'we share the concerns of intersex activists regarding the discomfort of society towards gender [sic] variances'[20]. Of course, each culture has different dominant ideas about sex, gender, and bodies, and for families trying to understand what to do when an intersex baby is conceived or born, it can be extremely difficult to find a way around them. Key difficult issues are rigid ideas about what bodies should look like, and what makes a boy/man or a girl/woman. These ideas are used to justify early medical interventions that can be very harmful to a child, and to an intersex person in later life as well.

Sometimes unnecessary medical interventions are performed because of prejudice towards LGBT people and of a false belief that it will stop a child becoming LGBT[21]. In fact, assigning a male or female sex without knowing the gender identity of the person that intersex person will become may lead to the child being transgender. Intersex people identify in lots of different ways – most identify with the sex they have been assigned to at birth, but many identify as transgender or non-binary. Many identify as heterosexual, but some identify as LGB, including those who have been subjected to early non-consensual medical interventions such as surgery. These are amongst the many reasons to wait until a child knows what sex/gender they are before performing irreversible surgeries or other interventions such as hormone treatment.

Other reasons why medically unnecessary, irreversible, and non-consensual medical interventions on intersex babies and children continue to be performed are because it can be difficult for families to imagine having an intersex child and to know how to look after them because there is so little intersex visibility and knowledge in our society. Social invisibility is a problem[22] which can be linked to secrecy, shame, and the perpetuation of damaging medical practices[23]. In one of the INIA projects, led by Sean Saifa Wall and based on Irish and English situations, we found there was almost no mention of intersex in an entire range of policy documents in areas such as education, healthcare, policing, and youth work. Where Intersex was mentioned at all, it was put together with LGBT, but there was no recognition that many of the issues faced by intersex people (such as having survived medically unnecessary early

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[18] Coke, E., Sheppard, S., & Liberty Fund. (2003). *The selected writings and speeches of Sir Edward Coke*. Liberty Fund; Karkazis, K. (2008). *Fixing Sex: Intersex, Medical Authority, and Lived Experience.* Duke University Press.

[19] Cornwall, S. (2020). Bodily Rights and Gifts: Intersex, Abrahamic Religions and Human Rights. *Culture, health and sexuality*, *23*(4), 533-547.

[20] Cools, M., Simmonds, M., Elford, S., Gorter, J., Ahmed, F., D'Alberton, F., Springer, A., & Hiort, O. (2016). Response to the Council of Europe Human Rights Commissioner's Issue Paper on Human Rights and intersex People. *European Urology*, *70*(3), 407-409.

[21] Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). Intersex/variations of sex characteristics and DSD citizenship in the UK, Italy and Switzerland. *Journal of citizenship studies*, *23*(8), 780-797.

[22] Council of Europe. (2015). *Human Rights and Intersex People*. Council of Europe Commissioner for Human Rights. https://rm.coe.int/16806da5d4

[23] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). *op. cit.*

childhood interventions) are particularly to intersex people[24]. Where there is a silencing about intersex, it is very hard for people who provide services (such as teachers, social workers, police, healthcare professionals and people working in the media) to help intersex people and their families, because they do not know what to do. For example, a teacher might be unsure how to deal with a situation where an intersex child is being bullied. Saifa's research project recommends interventions to ensure that intersex people are included and supported in society by putting policy and practice interventions in place, but there is much work to be done across all parts of society.

In 2015, the Council of Europe Commissioner for Human Rights described legal and bureaucratic barriers to intersex people having lives that are liveable, for instance birth certification requiring registration as M or F, a lack of legal protections, a lack of unspecified or non-binary options of documents such as passports in many countries (Australia, Malaysia, Nepal, New Zealand and South Africa allowed X on passports at time of writing) and the binaried categorisation by institutions such as sports bodies. Intersex people face high levels of discrimination[25]. Levels of social prejudice are high but vary considerably across European Member States[26]. Almost two thirds of intersex respondents in the second FRA LGBTI survey[27] felt discriminated in at least one area of life due to being intersex, for example housing, employment, and accessing services such as healthcare. Because intersex is not included in the list of protected characteristics in terms of legal protections from discrimination in many countries, people with sex variations are vulnerable to discrimination[28]. Protection from discrimination is enshrined in EU Treaties such as the Charter of Fundamental Rights of the European Union (Article 21) and Directive 2000/78/EC and the related secondary legislation. Intersex people can be protected on the grounds of 'sex characteristics'.

Embryo selection for IVF

Eugenicist practices concerning embryo selection, where people seek to have what they might consider a 'perfect' baby in line with what might be considered to be 'perfect' in their particular society is an important issue. These practices include pre-implantation genetic testing of embryos for intersex variations, meaning that in practice fewer babies with variations of sex characteristics are born in some countries[29]. The issue of life before birth poses particularly tricky questions, interwoven as it is with parental rights concerning choice[30]. However, this, and the related issue of prenatal screening, are problematic when it

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[24] Monro, S., Wall, S. S., & Wood, K. (2023). Intersex equality, diversity and inclusion and social policy: Silences, absences, and erasures in Ireland and the UK. *Critical Social Policy*, *0*(0). https://doi.org/10.1177/02610183231175055

[25] Monro, S., Carpenter, M., Crocetti, D., Davis, G., Garland, F., Griffiths, D., ... & Aggleton, P. (2021). Intersex: cultural and social perspectives. *Culture, Health & Sexuality*, *23*(4), 431-440.

[26] European Commission. (2019, September 23). *Eurobarometer on Discrimination 2019: The social acceptance of LGBTI people in the EU*. https://ec.europa.eu/info/policies/justice-and-fundamental-rights/combatting-discrimination/lesbian-gay-bi-trans-and-intersex-equality/eurobarometer-social-acceptance-lgbtiq-people-eu-2019_en

[27] European Union Agency for Fundamental Rights. (2020). *EU-LGBTI II: A long way to go for LGBTI equality.* https://fra.europa.eu/sites/default/files/fra_uploads/fra-2020-lgbti-equality-1_en.pdf

[28] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op. cit.*

[29] Danon, L. M. (2023). *To imagine and prevent future intersex bodies.* paper presented at the Centring intersex ssues: Global and local dimensions conference, online, 20-23 February 2023.

[30] Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). *op. cit.*

comes to supporting diversity. Intersex Human Rights Australia, an intersex advocacy and activism group, argues that the deselection of intersex traits is the same as deselection on the grounds of sex or ethnicity and should be prohibited, with information about diversities being given to parents[31].

Variations of sex characteristics are often identified during prenatal screening. As with any unexpected screening result, this can be distressing for parents-to-be and their families. Kyle Petersen, an intersex author, suggests that genetic testing can be beneficial in allowing parents to prepare for specific situations. He argues that foetal termination can be seen as an act of compassion:

> …where the foetus is experiencing an inherited extremely rare multisystem debilitating lethal physiology with a co-occurring intersex variation… For example, changes in Wnt4 gene can lead to both sex reversal and prenatal underdevelopment of the heart, lungs, and kidneys[32]. (2021, p.31).

However, instances of this severity are usually not the case and sadly terminations are carried out routinely for variations of sex characteristics where a baby could have a happy and productive life, simply because of outdated laws and practices. For example, in the UK, terminations of intersex foetuses can take place even up to the due date, simply because these variations are framed as severe disabilities in the law, and there is often a lack of information provision to parents[33]. Where proper information is provided, parents are likelier to decide to keep their baby. It is important that parents and families are provided with comprehensive information at the point where a prenatal diagnosis is made. This means providing information about relevant organisations including intersex-led ones, so parents can make informed choices for themselves and their families.

3. Birth and immediately afterwards

Families who experience the birth of an intersex baby will respond differently depending on whether they already knew about the variation, on their attitudes towards diversities, on social context, and how the birth is dealt with by healthcare professionals (HCPs) such as midwives and obstetricians. It is important to highlight that some parents see their unusual child as a gift[34]. Thinking about the birth and preparing for the new arrival can help smooth the process, regardless of variation. Of course, not all variations are apparent at birth, but in this section, we talk about those that are identified at birth or become apparent in early childhood.

Since the 1950s, where a variation of sex characteristics has been identified, these births have been treated as emergencies[35]. There is often pressure on the parents to decide 'what to do',

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[31] Carpenter, M. (2014*). Submission on the Ethics of Genetic Selection against Intersex Traits*. Intersex Human Rights Australia. https://ihra.org.au/25621/submission-ethics-genetic-selection-intersex-traits/

[32] Petersen, J. K. (2021). *A Comprehensive guide to intersex.* Jessica Kingsley Publishers, p. 31.

[33] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op cit.*

[34] De Clerq, E. & Streuli, J. (2019). Special parents for "special" children? The narratives of health care providers and parents of intersex children. *Narrative inquiry in bioethics*, *9*(2), 133-147.

[35] Viloria, H., & Nieto, M. (2020). *The spectrum of sex: The science of male, female, and intersex*. Jessica Kingsley Publishers.

especially because of social influences (for example to name the child and to declare whether it is a boy or girl) and other pressures such as the need to register the birth. The birth of a child with a variation of sex characteristics can be a shock to parents with little intersex awareness, especially when their child's variation is presented to them as a serious medical abnormality. It can be overwhelming for parents dealing with testing and other hospital related matters when a baby is judged to be abnormal. Also, in some cases, intersex babies can have other conditions that do need addressing urgently. The whole process can be traumatic, affecting bonding between parents and the child.

Sometimes, parents can be pressurised by specialists to decide and agree to irreversible interventions although they often regret these decisions later[36]. There are studies showing high levels of complications for surgical interventions, such as chronic pain, incontinence, damage to urinary function, sexual sensation, capacity for intimacy as an adult, and problems with psychological trauma including PTSD, suicidality, experiencing the medical interventions as sexual abuse and rape, and substance abuse as a teenager or adult[37]. More broadly, surgeries require anaesthesia, and when this takes place in early childhood it can be associated with increased levels of ADHD especially when the anaesthesia is for a long operation, or there are repeated anaesthetisations[38].

A paper from research group DSD-LIFE indicated poor adult levels of satisfaction with surgery and recommends that 'constructive genital surgery should be minimised and performed mainly in adolescence or adulthood with the patients' informed consent'[39]. Some research shows promising results for postponing irreversible interventions[40]. Typically, families can raise their child as a boy or a girl without major medical interventions, and then if the child changes their mind about their sex and/or gender later, it may be relatively easy to remedy this situation depending on the political climate in which the family lives[41].

At present, parents are often not offered non-surgical options[42,]. Unfortunately, some medical practitioners may have an investment in continuing with current practices, for a number of reasons, for example it may be good for their careers. Keeping unnecessary

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[36] Fisher, R. S., Espeleta, H. C., Baskin, L. S., Buchanan, C. L., Chan, Y. M., Cheng, E. Y., ... & Wisniewski, A. B. (2022). Decisional regret about surgical and non-surgical issues after genitoplasty among caregivers of female infants with CAH. *Journal of Pediatric Urology*, *18*(1), 27-33.

[37] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op. cit.*

[38] Sun, J., Zhu, C., & Jiang, H. (2021). Exposure to general anaesthesia in childhood and the subsequent risk of attention-deficit hyperactive disorder: A meta-analysis of cohort studies. *Asian journal of psychiatry*, 6, 102708.

[39] Köhler, B., Kleinemeier, E., Lux, A., Hiort, O., Grüters, A., Thyen, U., & DSD Network Working Group. (2012). Satisfaction with genital surgery and sexual life of adults with XY disorders of sex development: Results from the German clinical evaluation study. *Journal of clinical endocrinology & metabolism*, *97*(2), 577.

[40] Bougnères, P., Bouvattier, C., Cartigny, M., & Michala, L. (2017). Deferring surgical treatment of ambiguous genitalia into adolescence in girls with 21-hydroxylase deficiency: A feasibility study. *International journal of pediatric endocrinology*, *1*, 1-5.

[41] Abreu, R. L., Sostre, J. P., Gonzalez, K. A., Lockett, G. M., & Matsuno, E. (2022). "I am afraid for those kids who might find death preferable": Parental figures' reactions and coping strategies to bans on gender affirming care for transgender and gender diverse youth. *Psychology of sexual orientation and gender diversity*, *9*(4), 500.

[42] Liao, L. M., Wood, D., & Creighton, S. M. (2015). Parental choice on normalising cosmetic genital surgery: Between a rock and a hard place. *British medical journal,* 351. DOI: 10.1136/bmj.h5124.

interventions as standard practice makes it easier for medical practitioners and hospitals to avoid being sued when an unnecessary intervention goes wrong. It can be hard for parents/carers to stand up to medical practitioners, particularly specialists who have a high level of social status, and especially when the wellbeing of the child is dependent on the support of medical professionals.

The main medical protocol concerning DSD internationally, the 2016 update to the 2006 Consensus Convention guidelines states:

> Although parents are responsible for consenting to interventions believed on the basis of available evidence to be in the best interests of their child, their right to consent to non-medically necessary irreversible procedures that may adversely affect the child's future sexual function and/or reproductive capacity has been questioned, particularly when such parental decisions preclude the child's ability to be involved in decision making[43].

The 2006 Consensus Convention guidelines were purportedly aimed at creating patient centred care focusing on the psychosocial wellbeing of the individual and their family, encouraging psychosocial as opposed to surgical interventions. The 2016 update indicates an agreement amongst experts on delaying vaginal and gonadal surgeries until the individual can participate in decision-making; it encourages fully informed consent and decision making, as well as the postponing of surgeries that can be delayed in the interest of prioritizing sexual and reproductive function.

For parents, carers and/or family members, it is crucial to get all the information and support needed to make an informed choice about their child's care. This should include access to a specialist psychologist and/or social worker before any choices are made about interventions. Support should also include contact with intersex-led and peer support organisations[44]. There can be conflicts between different groups, for example a few patient and parent organisations (often funded by healthcare providers) support early irreversible interventions because, in some cases, these may work for people, but in doing so, overlook cases where interventions have gone wrong. It may be helpful for families to be aware that the studies found on the internet can be distressing to read (because they are very pathologising), and sometimes they contain pictures of intersex children's genitals, which is problematic.

Overall, families may be reassured to know there are happy healthy intersex people thriving in the world, and that it is possible to resist stigmatisation of an intersex child's variation. It is helpful to take an active and empowered approach to children's healthcare where possible, including, for example, learning about complaints, procedures, and any rights they may have to seek care at a different institution if they are not happy with the current one.

4. Infancy to adolescence

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[43] Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., & Mazur, T. (2016). *op. cit.*

[44] Magritte, E., Williams, J., Amyot, E., Usipuik, M., Sanders, C. (2023). Listening to individuals with differences in sex development or intersex and their families: "Not doing surgery does not mean doing nothing". *Hormone research in paediatrics*, 96(2), 228-237.

There are at least 40 variations of sex characteristics, each of which can play out in different and sometimes overlapping ways. A variation can be apparent before birth, at birth, or later (for example at adolescence). Of course, each child and family are unique, so it is hard to generalise about the range of experience intersex children may have. For families whose children were not subjected to serious medical interventions (such as surgery, vaginal dilation, or hormone treatment), the main issues may be dealing with families, friends, communities, child-carers, and teachers who are likely to have little intersex knowledge, and who may show prejudice because of this. More broadly, some countries have cultures which are at best unsupportive to bodily and sex diversities. Historically, families were told to keep their child's variation secret[45], and whilst family privacy is important, secrecy can be toxic to children, especially if they are lied to by parents or carers[46]. Therefore, it is preferable if families find ways to encourage their child to be proud of their body and comfortable about themselves, and to challenge any prejudice they may encounter while growing up.

Even for children who avoid unnecessary interventions there will be challenges, such as coping with visits to medical specialists for monitoring. Previous research shows that intersex children have been used to educate healthcare professionals (for example exposed for students to see), subjected to unnecessary painful and humiliating examinations, and even subjected to intimate photography while unclothed for research and education purposes. In any other setting, these experiences could be understood as sex abuse. Harrowing accounts from adults who have been subjected to these experiences as children or teenagers show that it is important for parents and carers to protect children from these experiences as much as possible, regardless of how difficult this may seem[47].

A few variations included under the intersex umbrella may in some cases involve minor or major learning difficulties or disabilities, for example dyslexia with XXY/Klinefelter syndrome. Children with these variations may benefit from early assistance, and early identification of the issues can be important. Whatever the variation, it may be necessary to educate teachers and others about the child, and to ensure that bullying is tackled, even though supporting intersex children should already be part of staff training. Unfortunately, there are few laws to ensure that intersex children will be supported and cannot be victimised at present, although of course this can be culture specific. Families may find there is little or no representation of intersex in their child's school lessons, or elsewhere. There is much work to do to make the world a more welcoming place for intersex children. However, there are useful suggestions in the literature[48], including 'whole-school' approaches where intersex peoples' issues are recognised and affirmed.

For families whose child or children have already been subjected to serious medical interventions, there may be additional challenges, for example supporting the child or children through major surgeries and aftercare, and finding ways to deal with the problems

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[45] Dreger, A. D. (ed.). (1999). *Intersex in the Age of Ethics*. University Publishing Group.

[46] Karkazis, K. (2008). *op. cit*.

[47] Viloria, H., & Nieto, M. (2020). *op. cit.*; Hart, B. & Shakespeare-Finch, J. (2021). Intersex lived experience: Trauma and posttraumatic growth in narratives, *Psychology and sexuality*, *13*(4), 912-930.

[48] Brömdal, A., Zavros-Orr, A., Lisahunter, Hand, K., & Hart, B. (2021). Towards a whole-school approach for sexuality education in supporting and upholding the rights and health of students with intersex variations. *Sex Education*, *21*(5), 568-583.

such as time missed from school and the impact this may have on peer relationships[49]. Surgery is often presented as a means to 'fix' non-normative bodies, reinforcing unrealistic expectations amongst parents[50]. Where families have allowed harmful interventions, or if the intersex variation is stigmatised within the family, there may be relationship difficulties due to, amongst a plethora of reasons, a breakdown in trust. As the child grows older, they may break contact with the family[51]. Overall, parents and other family members can have a really hard time, experiencing trauma as well as guilt and regret over unnecessary interventions, which may make it harder to support the child[52].

More positive accounts of parenting an intersex child can also be found. For example, one study found that parents linked with intersex communities had more information and were more able to challenge medical professionals, and make decisions that lead to no, or minimal, decisional regret[53]. Support groups for parents may be helpful for those parenting intersex children. Seasoned parents with well-developed coping skills may be able to help families develop confidence and cultivate parenting strategies that support recognition of children's autonomy and their right to make their own choices'[54]. Different families will find different strategies, but it is useful for them to remember that there are others out there dealing with similar situations.

5. Adolescence to adulthood

Many of the issues common amongst some children with variations of sex development, such as dealing with healthcare systems and fallout from early interventions, and ensuring that childcare and schooling is appropriate, will be relevant to older children and teenagers as well. There are some differences of course, for example some variations only become apparent during adolescence, when unexpected secondary sex changes occur, or if a girl does not begin her period along with her friends and classmates. Parental and family attitudes are important. If a young person is made to feel ashamed of their variation, this can contribute to social isolation, so it is helpful if there is openness and support available for the young person (whether or not they want to talk about their variation)[55].

For those young people learning about their variation during their teens, there may be a process of adjustment, and this can be challenging, for example if infertility should be diagnosed. At present, not many healthcare practitioners have the capacity to help intersex young people with issues such as fertility and sexuality, but supporting young people's choices

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[49] Jones, T., Hart, B., Carpenter, M., Ansara, G., Leonard, W., & Lucke, J. (2016). *Intersex: Stories and Statistics from Australia*. Open Book Publishers.

[50] Eden, J. (2020). *Building Professional Capacity to Combat Discrimination Against and Better Meet the Needs of Intersex Persons – BRING-IN. National Situational Analysis Report United Kingdom*. Report provided for the Rights, Equality and Citizenship (REC) Programme of the European Union. Unpublished.

[51] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op. cit.*

[52] Hart, B. & Shakespeare-Finch, J. (2021). *op. cit.*

[53] Davis, G. (2015). *Contesting Intersex: The Dubious Diagnosis*. New York University Press.

[54] Baratz, A. (2015). Parental choice on normalising cosmetic genital surgery. *British medical journal*, 351, DOI 10.1136/bmj.h5124

[55] Callens, N., Kreukels, B. P. C., & van der Grift, T. (2021). Young voices: Sexual health and transition care needs in adolescents with intersex/differences in sex developments. *Journal of pediatric and adolescent gynecology,* 34(2), 176-189.

about their lives in these areas is important[56]. This includes resisting unwanted medical interventions and examinations[57] or indeed making choices to have interventions that they themselves may want once they are old enough to give informed consent[58].

Children and young people who have variations of sex characteristics may need to take time to work through their identity issues[59]. Several studies about young intersex people show that for some of them, coming to terms with issues such as infertility and other differences such as short stature is important and can be hard[60]. However, Charlotte Jones (2020) found that one of the young women who contributed to her United Kingdom based study was glad she had found out about her Turner's syndrome and her infertility when she was 15, as she felt it gave her more time to plan for her future. Of course, not all young people with variations of sex characteristics are infertile, but many are infertile or may need healthcare interventions to protect fertility[61], so it may be useful to have timely discussions with healthcare providers and the young person about this.

Education settings can be challenging for intersex young people, for a number of reasons such as a lack of information, worries about managing body diversities, experiences of bullying and discrimination, and a failure of schools to include variations of sex diversities in their sex education programmes and other subjects such as biology. Some teens choose to stay strategically private about their intersex variations. There is need for more information for young people, for example about menstruation, fertility, sexuality, and for stigmatisation of diversities to be tackled[62]. Also, there are issues about the impact of stigma on peer relationships, for example bullying about hirsutism or delayed breast growth[63], which can be hard for young people to cope with. Traditional gender patterns (ideas that girls and boys have different interests, ways of behaving, and friendship patterns) could prove challenging to negotiate and breaches of those norms could lead to social sanctions, and bullying[64]. Young intersex people may experience loneliness, and difficulties with friendships and dating (such as a lack of confidence, fears of intimacy, not knowing how to disclose their variation, and boundary issues due to experiences of medical harm and abuse[65]). Finding networks of other

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[56] *Ibid.*

[57] Karkazis, K. (2008). *op. cit.*

[58] Steers, D., Andrews, G., Wiltshire, E., Ballantyne, A., Collings, S., & Stubbe, M. (2021). Young People with a Variation in Sex Characteristics in Aotearoa/New Zealand: Identity, Activism and Healthcare Decision-making. *Culture, health and sexuality, 23*(4), 457-471

[59] Steers, D., Andrews, G.; Wiltshire, E., Ballantyne, A., Collings, S., & Stubbe, M. (2021). *op. cit.*

[60] Jones, C. (2020). Intersex, Infertility and the Future: Early Diagnosis and the Imagined Life Course. *Sociology of health and illness*, 42(1), 143-156; Callens, N., Kreukels, B. P. C., & van der Grift, T. (2021). *op. cit.*

[61] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op. cit.*

[62] Lundberg, T., Roen, K., Kraft, C., & Hegarty, P. (2020). How young people talk about their variations in sex characteristics: Making the topic of intersex talkable via sex education. *Sex education*, 21(5), 552-567; Sperling, J. (2021). Comprehensive sexual health education and intersex (in)visibility: An ethnographic exploration inside a California high school classroom. *Sex education*, 21(5), 584-599.

[63] Meyer-Bahlburg, H. F. L., Reyes-Portillo, J. A., Khuri, J., Ehrhardt, A. A., & New, M. I. (2017). Syndrome-related stigma in the general social environment as reported by women with classical congenital adrenal hyperplasia. *Archives of sexual behavior*, *46*, 341-351.

[64] Henningham, M., & Jones, T. (2021). Intersex students, sex-based relational learning and isolation. *Sex education*, 21(5), 600-613.

[65] Petersen, J. K. (2021). *op. cit.*

young people who have variations of sex characteristics or who are allies can be very helpful[66] (for example InterAct in the USA, Youth&I in Australia, and IGLYO in Europe).

Like intersex children, intersex young people need access to appropriate healthcare, both in terms of their variation and any management that is needed, and in terms of wider healthcare provision. There seems to be a gap in many countries for intersex young people between specialist provision that is in place when they are children, and adult care, where there is a great lack of appropriate healthcare provision, including psychological care[67,68].

6. Adulthood

As with other life-stages, it is impossible to do more than provide an overview of some of the key issues that may face intersex people in adulthood. We briefly review some key issues here.

As discussed earlier, variations grouped under the intersex umbrella are diverse and can vary widely. Whilst there are good medical practitioners who show dedication to helping intersex people appropriately, there is nonetheless a lack of trained specialists and dedicated resourcing for intersex people's specific health needs, especially those needs of adults[69]. Some of these needs are due to the fallout from childhood interventions, for example osteoporosis due to removal of gonads or trauma-related illness. Others may be related to the variation itself, as in for example salt-wasting with CAH. More broadly, there is a lack of general knowledge about variations of sex development amongst healthcare practitioners, which not only prevents proper care from being given, but can also lead to shaming situations where intersex people are asked inappropriate questions by medical staff, sometimes out of curiosity. Previous negative experiences can make intersex people reluctant to seek medical help for anything, even when help is needed[70]. There is a pressing need for more data collection, resourcing, and better training for healthcare professionals, and this should be informed by robust consultation with intersex-led NGOs, as their lived expertise should guide information about what is required[71].

There is no avoiding the fact that trauma is common amongst the adult intersex population. The key reason for this is the appallingly difficult experiences that many of them have been subjected to non-consensual and irreversible medical interventions[72], but other factors can also impact, including experiences of childhood stigmatisation, bullying, and discrimination[73].

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[66] Steers, D., Andrews, G.; Wiltshire, E., Ballantyne, A., Collings, S., & Stubbe, M. (2021). *op. cit.*

[67] Gramc, M., Streuli, J., & De Clercq, E. (2021). Multidisciplinary teams caring for people with variations of sex characteristics: A scoping review, *BMJ paediatrics open,* 5(1): e001257.

[68] Crocetti, D., Berry, A., & Monro, S. (2023). Navigating the complexities of adult healthcare for individuals with variations of sex characteristics: from paediatric emergencies to a sense of abandonment. *Culture, Health & Sexuality*, 1-14.

[69] Beale, J. M., & Creighton, S. M. (2016). 'Long-term health issues related to disorders or differences in sex development/intersex'. *Maturitas*, 94, 143–148.

[70] Crocetti, D., Berry, A., & Monro, S. (2023). *op. cit.*

[71] Monro, S., Crocetti, D., & Yeadon-Lee, T. (2019). *op. cit.*

[72] Petersen, J. K. (2021). *op. cit.*

[73] European Commission. (2019, September 23). *op. cit.*

Levels of social prejudice are high, but can vary considerably across EU Member States[74]. Social invisibility is a problem[75] which can be linked with secrecy, shame, and perpetuation of damaging medical practices[76]. For example, a study of attitudes in the Dutch and Flemish populations showed that most respondents did not know what 'intersex' meant[77]. Almost two thirds of intersex respondents in the second FRA LGBTI survey[78] felt discriminated in at least one area of life due to being intersex. Another issue can be political use of intersex issues by non-intersex others without the guidance of intersex people (such as trans activists or feminists) which can be damaging for intersex peoples' ability to define themselves and their causes[79]. Intersex people can of course be trans and/or feminists, but do not necessarily identity as either.

Because intersex is not included in the list of protected characteristics in many European countries, people with sex variations are vulnerable to discrimination[80]. For example, if they need to take medical leave whilst at work, they cannot access rights in the same way that a transgender person undergoing render confirmation surgery can in some EU Member States. Protection from discrimination is enshrined in EU Treaties such as the Charter of Fundamental Rights of the European Union (Article 21) and Directive 2000/78/EC and the related secondary legislation. Intersex people can be protected under the ground of 'sex characteristics', but there is no case law yet to support this.

Gender identity and sexual identity issues can become pronounced for some adults with variations of sex characteristics. For instance, Hida Viloria struggled 'for years' trying to choose between M and F gender identities, began speaking about this in late 1990s; their experience was of what known as 'gender-fluid' today. Hida now identifies as non-binary and has been loved and accepted as such[81]. In another example, a research contributor identified as intersex for some years, then found this unsatisfactory and identified as a variant asexual male[82]. Trajectories vary widely, but gender journeys can be made more difficult by incorrect gender assignment in childhood. For example, a mixed methods study with 78 intersex people in Germany (2002-8) found that of the 69 people with more than one DSD, only 75% were satisfied with their gender allocation. 9% said they had changed gender and 27% had a mixed two-gender identity or neither male nor female[83].

As we have already shown, family life can be difficult for people with variations of sex characteristics, due to complicity of parents in unnecessary medical treatments and the resulting fallout that may take place as the child matures, but also due to stigma and stresses

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[74] Council of Europe Commissioner for Human Rights. (2015). *op. cit.*

[75] Crocetti, D., Monro, S., Vecchietti, V. & Yeadon-Lee, T. (2021). *op. cit.*

[76] Khanna, N. (2021). Invisibility and trauma in the intersex community. *Violence against LGBTQ+ persons: Research, practice, and advocacy*, 185-194.

[77] van Lisdonk, J. (2014). Living with intersex/DSD. An exploratory study of the social situation of persons with intersex/dsd. Netherlands Institute for Social Research.

[78] European Union Agency for Fundamental Rights. (2020). *op. cit.*

[79] Eden, J. (2020). *op. cit.*

[80] Monro, S., Crocetti, D., Yeadon-Lee, T., Garland, F., & Travis, M. (2017). *op. cit.*

[81] Viloria, H., and Nieto, M. (2020). *op. cit.*

[82] Petersen, J.K. (2021). *op. cit.*

[83] Schweizer, K., Brunner, F., Handford, C., & Richter-Appelt, H. (2014). Gender experience and satisfaction with gender allocation in adults with diverse intersex conditions (divergences of sex development, DSD). *Psychology and sexuality*, 5(1), 56-82.

associated with managing an oftentimes hostile social environment. Some family relationships break down over time or are fractured from the beginning, but, as adults, some intersex people manage to rekindle relationships with parents and other family members, sometimes by agreeing to put the past behind them.

Other key issues include the impact on family relationships where members carry variations genetically, the effects of considering or having terminations[84], and issues associated with sterility. This affects, for instance, many people with Klinefelter syndrome, complete androgen insensitivity syndrome, partial androgyn insensitivity syndrome, and Turner syndrome[85]. There does not seem to be much literature about how intersex people have managed infertility and family building, but some intersex people who cannot procreate biologically choose to adopt children instead.

In terms of intimate relationships, existing research shows that early surgeries can impact severely on capacity to be intimate and enjoy sex. For example, one intersex person said that: '…My clitoris is gone… My vagina looks really fucked up…There's some scar tissue there and… penetration hurts… don't do surgery no matter what they say' (Pidgeon, age 23)[86]. It is not just the physical pain that can result from these interventions, but the emotional and identity fallout that causes problems. For example, one researcher analysed posts on the website BodiesLikeOurs.org to explore issues regarding intimacy and found that some people with sex variations who had important aspects of themselves changed without giving consent lacked the capacity to generate the sense of 'self' needed as a basis for an intimate relationship. She also found that another major hazard regarding intimacy and sexuality is that some people with sex variations experience direct rejection and discrimination from partners or potential partners[87]. Even the industries surrounding sex are discriminatory, for example a lack of suitable sized condoms for micropenises. Some intersex people also engaged in risky sex as a means of validating their sexuality[88]. Unfortunately, some people with sex variations are target for unwanted sexual attentions due to their status as intersex[89]. People with variations of sex characteristics have strategies for managing potential discriminations, from avoiding sex altogether even into later life[90] to using non-normative sexual techniques[91], and open disclosure about sex variations[92].

More generally, people with variations of sex characteristics may use a variety of means to create liveable lives. Coping mechanisms used by intersex people include for example focusing on work or talents but also less life-enhancing methods such as withdrawal, denial, repression, cognitive dissonance, and 'keeping up appearances'[93]. 'Identity work', where

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[84] Alderson, J., Madill, A., & Balen, A. (2004). Fear of devaluation: Understanding the experience of intersexed women with androgen insensitivity syndrome. *British journal of health psychology*, 9(1), 81-100

[85] Jones, C. (2020). *op. cit.*

[86] Davis, G. (2015). *op. cit.*, 92.

[87] Frank, S.E. (2018). Intersex and intimacy: Presenting concerns about dating and intimate relationships. *Sexuality and culture*, 22, 127-147.

[88] Davis, G. (2015). *op. cit.*, 92.

[89] Meyer-Bahlburg, H. F. L., Reyes-Portillo, J. A., Khuri, J., Ehrhardt, A. A., & New, M. I. (2017). *op. cit.*

[90] Davis, G. (2015). *op. cit.,* 92.

[91] Frank, S. E. (2018). *op. cit.*

[92] Karkazis, K. (2008). *op. cit.*

[93] Hart, B. & Shakespeare-Finch, J. (2021). *op. cit.*

people reflexively consider and address their subjectivities over time, is a fairly pronounced theme in the literature. For example, Georgiann Davis described her shock and confusion at the lies the medical profession had given her regarding her condition; she was told to have surgery due to ‘health risk’. She asked herself ‘Was having an intersex trait that horrible? I remember thinking I must be a real freak if even my parents hadn’t been able to tell me the truth’[94]. It took her a decade to be able to face the situation. However, she then went on to become a prominent and successful author in the field of intersex studies.

What are the key facets of identity work that can contribute to living a positive life? Shifts towards post traumatic growth are reported as including accessing information, affirmative language, knowing oneself, accepting one’s body, and getting the right hormone therapy or other medical treatment. Peer support can be very important including meeting others like oneself, being ‘out’ and accessing new social and romantic opportunities[95]. Some intersex scholars discuss the centrality of reclaiming the body, which can include surgery[96]. For others, information-gathering, activism to effect positive change, and seeing institutions such as the UN starting to address intersex people’s human rights are all important[97].

7. Older people

Older intersex people face the same issues as younger intersex adults, as outlined above, including long-term impacts of non-consensual, irreversible medical interventions performed on them when they were infants or children (except in the instances where they were born before 1950s norms about early intersex surgeries were brought in). This section of the book is drawn from a published paper written by Addy Berry and Surya Monro, as part of the INIA project[98]. As with younger intersex adults, coping mechanisms include the arts and self-expression, and social support and community.

Overall, intersex adults report worse physical and mental health than controls[99] although older intersex people report better mental health that younger intersex people, which may be due to resilience or because intersex people with better mental health perhaps live longer lives. Overall, older intersex people have frequently experienced violations of their sexual and reproductive rights and right to bodily integrity. Higher levels of disability have been reported amongst older intersex people than amongst the general population[100]. Disability is, for many intersex people, constructed at the point of medical intervention, leaving them with functional disabilities that profoundly impact the remainder of their lives; for example, those

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[94] Davis, G. (2015). *op. cit.*, 4

[95] Davis, G. (2015). *op. cit.*, 92.

[96] Morland, I. (2005). The glans opens like a book: Writing and reading the intersexed body. *Continuum: Journal of media and cultural studies*, 19(3), 335-348.

[97] Viloria, H., & Nieto, M. (2020). *op. cit.*

[98] Berry, A., & Monro, S. (2022). Ageing in obscurity: A critical literature review regarding older intersex people. *Sexual and reproductive health matters*, 30(1), 44-55.

[99] Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., & Zieselman, K. et al. (2020). A national study on the physical and mental health of intersex adults in the U.S.. *PLoS ONE*, 15(10), e0240088.

[100] Skarin Nordenvall, A., Norrby, C., Butwicka, A., Frisén, L., Nordenström, A., Almqvist, C., & Nordenskjöld, A. (2017). Psychosocial outcomes in adult men born with hypospadias: A register-based study. *Plos ONE*, 12(4), e0174923; Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., & Zieselman, K., et al. (2020). *op. cit.*

that have undergone gonadectomies in childhood are left with a higher risk of developing osteoporosis later on[101]. Mental health problems are common, for example one study found that 53% of intersex participants reported their own mental health as fair or poor, with little variation according to age group[102] and the same study found that 18.3% of intersex participants over 40 years of age were disabled or unable to work, while 77.6% reported worrying about meeting expenses with their current income. Employment discrimination against intersex people has been documented; for example, a large trans-European survey reported that 31% of intersex respondents felt discriminated against at work[103]. Legal difficulties may arise later in life for couples where either or both parties are intersex and these could impact visitation, decision making and inheritance[104].

Research from paediatric endocrinologists and urologists underscores the difficulty in accurately assigning gender to an intersex infant[105]. Much is risked for the intersex person accidentally allocated to a transgender existence, considering the disproportionately high rates of discrimination and violence faced by the transgender [SM1] community[106]. There is little if any literature exploring the lives of older intersex people assigned an incorrect gender at birth.

Intersex people in later life face several potential disadvantages in regard to social support in later years. Increased risk of loneliness is likely for a plethora of reasons[107]. Early medical interventions have led to infertility for many intersex people[108], reducing the possibility they will be surrounded by children and grandchildren in their later years. High levels of harassment towards intersex people in public spaces have been reported, for example a European survey showed that 42% of intersex people are afraid to go out in public spaces due to the risk of attacks and abuse[109]. Such a high level of active discrimination may affect older

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[101] Kosti, K., Athanasiadis, L., & Goulis, D. G. (2019). Long-term consequences of androgen insensitivity syndrome. *Maturitas*, 127, 51-54.

[102] Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., & Zieselman, K, et al. (2020). *op. cit.*

[103] European Union Agency for Fundamental Rights. (2015). *op. cit.*

[104] Latham, J. R., & Barrett, C. (2015). Appropriate bodies and other damn lies: Intersex ageing and aged care. *Australasian journal on ageing*, 34, 19-20.

[105] Cools, M., Nordenström, A., Robeva, R., Hall, J., Westerveld, P., Flück, C., & Pasterski, V. (2018). Caring for individuals with a difference of sex development (DSD): a consensus statement. *Nature reviews endocrinology*, 14(7), 415-429; Babu, R., & Shah, U. (2021). Gender identity disorder (GID) in adolescents and adults with differences of sex development (DSD): a systematic review and meta-analysis. *Journal of pediatric urology*, 17(1), 39-47.

[106] Veldhuis, C. B., Drabble, L., Riggle, E. D., Wootton, A. R., & Hughes, T. L. (2018). 'I fear for my safety but want to show bravery for others': Violence and discrimination concerns among transgender and gender-nonconforming individuals after the 2016 presidential election. *Violence and gender*, 5(1), 26-36.

[107] Hughes, M. (2016). Loneliness and social support among lesbian, gay, bisexual, transgender and intersex people aged 50 and over. *Ageing and society*, 36(9), 1961-1981.

[108] Méndez, J. E. (2013). *Report of the Special Rapporteur on torture and other cruel, inhuman, or degrading treatment or punishment*. Office of the High Commissioner for Human Rights. https://www.ohchr.org/sites/default/files/Documents/HRBodies/HRCouncil/RegularSession/Session22/A.HRC.22.53_English.pdf ; Rowlands, S., & Amy, J. J. (2018). Preserving the reproductive potential of transgender and intersex people. *European journal of contraception & reproductive health care*, 23(1), 58-63.

[109] European Union Agency for Fundamental Rights. (2015). *The Fundamental Rights Situation of Intersex People.* https://fra.europa.eu/sites/default/files/fra_uploads/fra-2015-focus-04-intersex_en.pdf

intersex people, limiting opportunities for friendship and romance due to a lack of intersex awareness amongst the public[110].

As there is little research on ageing intersex bodies, medical staff may fail to accurately predict the needs of older intersex people and that the bodies of intersex patients might not fit the expectations of carers[111]. Ageing intersex people entering retirement homes and retirement communities may harbour concerns about living amongst older non-intersex people who may already be less accepting and tolerant of anyone they perceive to deviate from societal or biological norms. A fear of reprisal, discrimination and violence is to be expected, especially when much of the care provided is by organisations with religious affiliations[112]. Whilst home care may provide an alternative for those apprehensive about entering a care facility, older intersex people may also fear suffering abuse and humiliation from carers at home over variation-related, or surgery-related, bodily differences. Although ageing intersex people might fear being left to fend alone in their final years, they might also fear the loss of the intersex community they relied on for support.

It is imperative that the needs of ageing intersex people are understood and addressed both for their benefit and to avoid contributing to overburdened future healthcare systems. More broadly, it is vital that adequate training be provided for medical and care professionals tasked with caring for older intersex people during one of the most vulnerable periods of their lives. Switzerland provides an exemplar with its plans to open its first intersex inclusive LGBTI elder care homes in 2025[113]. There is also a pressing need for legal reform to protect older intersex people, and policies to tackle discrimination.

For families, supporting an older intersex family member may include addressing some of the above issues, in a caring way that fits the needs of that particular person. If a family member is no longer independent, it is necessary to assess and educate potential carers and institutions that will be looking after them, acting as the family member's advocate in the same way that a family member would for any other older person but with awareness of the specific harms and discriminations, they may have experienced or may still face.

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[110] Hughes, M. (2018). Health and well-being of lesbian, gay, bisexual, transgender and intersex people aged 50 years and over. *Australian health review*, 42(2), 146-151.

[111] Barrett, C., & Crameri, P. (2015). An extra degree of difficulty: An evidence-based resource exploring the experiences and needs of older LGBTI carers and the carers of older LGBTI people. Australian Research Centre in Sex, Health and Society, La Trobe University, Melbourne. https://carersqld.com.au/wp-content/uploads/An-Extra-Degree-of-Difficulty-1.pdf

[112] Latham, J. R., & Barrett, C. (2015). Appropriate bodies and other damn lies: Intersex ageing and aged care. *Australasian journal on ageing*, 34, 19-20.

[113] Swissinfo. (2020, July 12). *Zurich to open Switzerland's first LGBTI elder care homes.* https://www.swissinfo.ch/eng/zurich-to-open-switzerland-s-first-lgbti-elder-care-homes/45898136

Medical snapshot

The standards of care for people with variations of sex characteristics have in the last decades recognised the importance of the child's decision-making process in relation to intersex. Yet, practice has not completely changed. There are still health care providers who operate on children assuming it is in the best interest of the child, but their opinions are based on social expectations. The 'do no harm' principle has purportedly been embraced as the core principle in the care for children with variations with sex characteristics, and it should be a guiding principle, but providing intersex care and informing parents presents a difficult task for some care professionals. Health care professionals should inform and guide parents who are often distressed by the information of having a child with VSC, while providing patient-centred care that prevents/minimises medical issues, feelings of shame, stigma, and distress.

Legal snapshot

International and regional bodies like the United Nations, the Council of Europe and the European Parliament have played a leading role in recognising that intersex people are subjected to widespread human rights violations[114]. These violations include Intersex Genital Mutilation (IGM), non-vital medical interventions on minors, discrimination, and a lack of state protection from such abuses[115]. The international and regional European bodies recognise that non-consensual medically unnecessary surgeries and other procedures on intersex children constitute harmful practices and they have made several recommendations including State enactment of legislation to prohibit these practices[116]. These recommendations also include the formation of gender-neutral markers for birth registration/certificates[117], access to medical records[118], the formation of interdisciplinary counselling and peer support to intersex persons and their families[119], and for the states to raise awareness about intersex[120].

Despite the frameworks produced at the international and regional levels, it has been difficult to implement human rights for intersex people at the national level. Whilst countries like Germany, Greece, Malta, Portugal, and Spain have taken measures for the protection of intersex human rights[121], most nations have not formulated any laws for intersex protection and there is a pressing need for research about the effects of this on intersex people. For further reading on the international, regional, and national legal protection for intersex people, you can refer to the INIA Human Rights eBrief[122].

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[114] Council of Europe. (2015). op. cit.

[115] Ghattas, D. (2013) *Human rights between the sexes: A preliminary study on the life situations of inter* individuals*. Heinrich-Boll-Stiftung; Carpenter, M. (2016). The human rights of intersex people: Addressing harmful practices and rhetoric of change. *Reproductive health matters*, 24(47), 74-84.

[116] Ní Mhuirthile, T., Dixit, S., Zelayandía González, E., Lum, S., Mestre Martinez, Y. M., Aegerter, A., & Suess Schwend, A. (2022). *Human rights* eBrief. INIA/Dublin City University, https://doras.dcu.ie/27292/1/INIA%20Human%20Rights%20eBrief%2C%20final%2022.05.26%20ML.pdf.

[117] European Union Agency for Fundamental Rights. (2015). *op. cit.*

[118] European Parliament. (2019). *Resolution 2018/2878 (RSP) of 14 Feb 2019 on the rights of intersex people OJ C 449/142*. https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52019IP0128

[119] Council of Europe. (2015). *op. cit.*

[120] Council of Europe Parliamentary Assembly. (2013). *Resolution 1952 (2013) on children's right to physical integrity.* https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174

[121] Middleton, L. (2023, March 2). Explainer: What is intersex surgery and where is it banned? Openly. https://www.openlynews.com/i/?id=d24d7290-e353-4c47-b412-03ccad0ee34c

[122] Ní Mhuirthile, T., Dixit, S., Zelayandía González, E., Lum, S., Mestre Martinez, Y. M., Aegerter, A., & Suess Schwend, A. (2022). *op. cit.*

Chapter 2: Parents and siblings

Addy Berry & Audrey Aegerter

The previous chapter has highlighted how variations in sex characteristics (VSC) can affect the life of intersex people and their parents. This impact is not momentary; it has life-long repercussions. Hereafter, we discuss how the medicalisation and pathologisation of an intersex child impact both the parents and the siblings. It addresses how parents and siblings negotiate the medicalisation of one family member. Furthermore, we intend to display generational differences. The chapter is based on in-depth interviews with intersex individuals and analyses of medical and sociological literature. The data were collected in two research projects that are part of the INIA Programme, one aiming to reveal the issues faced by older (50+) intersex people by exploring their lived experiences and life histories, and another focusing on the emergence of intersex activism in Europe.

For many intersex people, their beginnings are shrouded in secrecy and stigma, which can negatively affect their relationships with parents, siblings, and other family members. If the intersex child is raised in what might be considered a religious or conservative environment, stigma and secrecy may be exacerbated. Having a child can be stressful, however, some situations may add additional stress — for instance, if the child requires further medical attention. Much research has been conducted on the parental experiences of children with a disability, examining, among other things, parental attachment, and distress. Howe[123], for example, maintains that the cause for insecure attachment is the 'interaction between children with disabilities and the caregiver's state of mind with respect to the attachment', affecting the 'sensitivity, communication and security of attachment'.

While we do not understand intersex variations as disabilities, there may be overlaps in parental experiences. Indeed, intersex variations can be perceived as congenital disorders, initiating a process of medicalisation of the child by multidisciplinary teams of doctors. In most European countries, this aligns with the last internationally accepted medical recommendations, namely the Consensus Statement of 2006[124], and renewed 2016[125]. However, some European countries have drafted their recommendations, as is the case in Switzerland, or have drafted laws, as is the case in Malta, Germany, Portugal, Spain, or Iceland. While there has yet to be research informing about the impact of such rules, researchers and activists in Switzerland have pointed out that the 2012 national ethics recommendations are only partially followed[126]. Either way, when a child goes through a

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[123] Howe, D. (2006). Disabled children, parent–child interaction and attachment. *Child & family social work*, 11(2), 95-106.

[124] Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., and Society, L. W. P. E. (2006). Consensus statement on management of intersex disorders. *Journal of pediatric urology*, 2(3), 148-162.

[125] Lee, P. A., Nordenström, A., Houk, C. P., Ahmed, S. F., Auchus, R., Baratz, A., & Mazur, T. (2016). Global disorders of sex development update since 2006: perceptions, approach and care. *Hormone research in paediatrics*, 85(3), 158-180.

[126] Abate, D. (2018). *Variations du développement sexuel (VDS) : Sortir du paradigme Johns Hopkins, les évolutions de la prise en charge du patient dans la prise en charge biomédicale des VDS*. MA dissertation. Université de Lausanne ; De Clercq, E., & Streuli, J. (2019). *op. cit.* ; Zwischengeschlecht. (2021). *NGO Report*

process of medicalisation, parents are required to attend additional medical appointments. They are also often in a situation of distress.

Parental distress is one of the reasons given by doctors for surgical intervention on an intersex child. However, medical research, like that conducted by Jürg Streuli and his team[127] at the University Hospital of Zürich, shows how the setting around the announcement of 'diagnosis' impacts stress and decision-making of parents: doctors wearing white coats, using pathological terminologies, and not congratulating parents on the birth of the child are all indications that the child has a problem, and this increases parental distress.

Whether the child is intersex, has a disability or has another condition that may require medical attention, parents are expected to take on an extra role: they become advocates for their child's needs, care, and best interests. In the case of the birth of an intersex child, parents are expected to make difficult decisions: should they allow surgeons to operate on their child? If so, when? Should they explain these operations to their child and family? If so, how? How will they manage school and other social outings if the variation becomes apparent to others? Taking the route of medicalisation may require an active parental role consisting of regular medical meetings and pre- and postoperative care[128]. Parents are sometimes also directly involved in medical acts, such as vaginal dilatation[129], which can be a traumatic experience for both the child and the parent. Often, the caring parent is the mother[130]. Except for specific variations, there is often an absence of peer-support offers for parents, making them feel alone. Sometimes without meaning to, the intersex child is treated by their parents as different from their siblings, perhaps for not fulfilling the parents' expectations, or perhaps for not measuring up to expected gender norms. Siblings might be ignorant of the situation but can feel left out. For example, hospital stays might be framed as holidays, and time spent with a parent to attend a medical appointment can be envied by an uninformed or misinformed sibling.

Often, medical practitioners instruct parents not to talk to friends or family, including the intersex child themselves, about the child's variation. Doctors may have told them about their child's variation in a pathologising way that gives rise to shame and embarrassment related to their intersex child. Research suggests that parents are often misinformed or guided towards surgical solutions[131], but evolutions have occurred since the start of the first medical paradigm, the Optimal Gender Policy (OGP). The OGP, developed in the 1950s in the Johns Hopkins Hospital (USA), pushed for a surgical solution as early as possible and toward

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(for Session) to the 5th to 6th Report of Switzerland on the convention on the rights of the child (CRC). *https://intersex.shadowreport.org/public/2021-CRC-Swiss-NGO-Zwischengeschlecht-Intersex-StopIGM.pdf*

[127] Streuli, J. C., Vayena, E., Cavicchia-Balmer, Y., & Huber, J. (2013). Shaping parents: impact of contrasting professional counseling on parents' decision making for children with disorders of sex development. *Journal of sexual medicine*, 10(8), 1953-1960.

[128] Larrieu, G. (2022). Gouverner les corps sexués. Les variations du développement sexuel des enfants au prisme du pouvoir médical et familial. *Terrains/Théories*, 16. https://doi.org/10.4000/teth.4938

[129] Kessler, S. J. (1998). *Lessons from the Intersexed.* Rutgers University Press

[130] Petit, L. (2018). *De l'objet médical au sujet politique : récits de vies de personnes intersexes*. MA dissertation. Université Paris 8 ; Kessler, S. J. (1998). *op. cit.* ; Larrieu, G. (2022). *op. cit.*

[131] Timmermans, S., Yang, A., Gardner, M. et al. (2018). Does patient-centered care change genital surgery decisions? The strategic use of clinical uncertainty in disorders of sex development clinics. *Journal of health and social behavior*, 59(4), 520-535.

misinforming the parents. As such, it recommended telling them that their child was 'not finished' rather than 'half-half'[132]. It might therefore be unsurprising that many parents consented to early medical interventions. Furthermore, the authors of OGP suggested keeping this situation secret, which has the potential to contribute to shame and misinformation. In 2006, the 'Consensus Statements on Management of intersex disorders' aimed to include parents' and patients' concerns in decision-making[133]. However, medical research indicates this is still lacking[134].

1. Relationship with parents

Many people are unaware of the existence of intersex people. Indeed, since the 1950s, early medical treatments, including surgeries and hormone therapy, have contributed to rendering intersex traits invisible. Increased intersex visibility is largely a recent phenomenon and almost entirely due to work by the intersex community and its allies. Due in part to social invisibilisation, many parents become aware of intersex variations and their medical 'treatment' at the birth of their own intersex child or when their child is diagnosed (as often, this does not happen right after the birth). Frequently, there is insufficient support or information given to the parents of intersex children by medical practitioners. The parents may not have the language or skills to discuss these matters in an age-appropriate way with their children. Parents may wish to be connected with other parents of intersex children or wish to have access to more information, and they may have questions on how or what to tell their friends and family or how to deal with schools, babysitters and relatives who might happen to see the child's naked body. Rarely are parents of intersex children being put in contact with other parents of intersex children. Often when parents of intersex children connect, it is through other parents and patient organisations: groups that may embrace pathologisation of intersex variations. In the medical setting, parents are often introduced to a multidisciplinary team that tends to treat the variation as a medical emergency and only presents possible surgical and hormonal solutions rather than a holistic approach that considers non-medical options.

Rarely are parents of intersex children connected by medical professionals to intersex adults or intersex organisations. However, this has been one of the demands of intersex organisations since the beginning of intersex activism. In 2006, the Intersex Society of North America published a *Handbook for parents*[135], as did OII-Europe in 2018[136]. In Germany, parents of intersex children have been welcomed and participated in the support group meetings of XY-Frauen since the group's founding. The Collectif Intersexes Activistes in France also created a mailing list for parents to exchange information with each other, and parents are at the forefront of the movement in some countries, as in Greece. In the US, two parents

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[132] Money, J., Hampson, J. G. and Hampson, J. L. (1956). Sexual incongruities and psychopathology: The evidence of human hermaphroditism. *Bulletin of the Johns Hopkins Hospital*, 98(1), 43-57.

[133] Hughes, I. A., Houk, C., Ahmed, S. F., Lee, P. A., & Society, L. W. P. E. (2006). Consensus statement on management of intersex disorders. *Journal of pediatric urology*, 2(3), 148-162.

[134] Timmermans, S., Yang, A., Gardner, M. et al. (2018). *op. cit.*

[135] Intersex Society of North America. (2006). *Handbook for parents*. https://isna.org/books/handbook_for_parents/

[136] OII Europe. (2018). *Supporting your intersex child – A parents' toolkit*. https://www.oiieurope.org/supporting-your-intersex-child-a-parents-toolkit/

wrote a book entitled *Raising Rosie*[137] about raising their intersex child without surgery. However, these parents happened to have encountered resources encouraging them to look, understand, critically interpret, and even oppose the medical establishment in some instances.

When healthcare professionals or psychosocial care-givers neglect to connect parents of intersex children to intersex adults it can deny the new parents support opportunities as well as opportunities to explore other options for their child, including the opportunity to insist on non-surgical care pathways. Not connecting parents of intersex children and intersex adults can deprive parents of a valuable resource to guide their child throughout their life and to supply them with information in a non-pathological and age-appropriate way. The intersex child may harbour feelings of betrayal and abandonment towards their parents for having been brought to the hospital to be made to undergo surgeries and other procedures that may continue to affect the child negatively throughout their life. Some parents may experience feelings of guilt and remorse upon learning that their child has suffered greatly as a result of early medical procedures, believing they might have betrayed their child or allowed harm to come to them by following the advice of medical practitioners that they trusted. For example, one study on parents' decision regret related to hypospadias surgery[138] found a 65.2% regret rate. Parents of a child with Klinefelter syndrome might experience regret over a failure to help their child get diagnosed so that they might access appropriate medical care.

Some intersex people may have difficult relationships with their parents and therefore find the presence of parents in support group meetings triggering. Parents who join these groups may have already permitted operations to be performed on their child, or they may be considering it. This may contribute to creating a place that feels unsafe for some intersex people who have had surgeries performed on them that they did not consent to. One participant explains how it felt for her when she joined XY-Frauen in the early 2000s:

> I wanted to do something to prevent these surgeries in the future. I was also moved by these parents. There were some parents at the meeting. There were so desperate. They were crying and did not know what to do... Oh! I must add that most of the babies were already castrated and/or had surgery on their genitals. There was not one child in this self-help group that was intact.
> Audrey Aegerter: And the parents were overwhelmed by hearing all your stories, I suppose.
> Yes, it was difficult. It was very, very difficult. This was always a discussion amongst the group because... We had... I mean, the parents came and wanted to listen to us, but most of the intersex people did not want that. They did not want their parents to sit in the room when we shared our stories. (...) It was really difficult to find a balance because we wanted our privacy, cry together... (...) some parents thought our role was to tell them: 'yeah it's ok'. Some of us were angry and said: 'no, it's not ok. You've let somebody mutilate your child' (Interview 27, 15.12.2022).

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[137] Lohman, S., & Lohman, E. (2018). *Raising Rosie: Our story of parenting an intersex child*. Jessica Kingsley Publishers.

[138] Vavilov, S., Smith, G., Starkey, M., Pockney, P., & Deshpande, A. V. (2020). Parental decision regret in childhood hypospadias surgery: A systematic review. *Journal of paediatrics and child health*, *56*(10), 1514-1520.

While some intersex people remain in close contact with their parents throughout their lives, others might go for years without communicating, only repairing their relationship in later life by mutually agreeing not to discuss past events but to focus instead on the future of their relationship. Early open and honest discussion between parents and their intersex child and other children may do much good in fostering healthy family relationships and building strong foundations for the intersex child's relationships with others outside the home. Many participants felt anger and resentment towards their parents. Some talk openly about their experiences, as shown in the following interview extract:

> There were only my parents with whom I could have talked about it... And I ruled that out for the first time for various reasons... Among other things, because it looked to me as if they had not told me the truth for 12 years... And that also upset the relationship... At least from my side…
>
> [...]
>
> My parents, I can now talk openly about my activism... They also support me fully. My sister... Today, my whole family supports me with everything and points their friends to documentaries on the topic and so on... And... Yes... They all do that... They are actually also activists for the topic without being activists themselves. (Interview 2, 25.01.2022, translated from German by the authors).

What is interesting from this interview extract is that this person discovered that she was intersex when she was 12 and being medicalised. This is quite uncommon, as secrecy is at the centre of the management of intersex cases. Parents are implicitly or explicitly instructed not to talk about 'this' to their child. It was recommended that parents say that the child has a malformation, was not finished and that medicine was here to help. In some cases, parents believed what they were told to say. In the above case, the parents eventually told their child, helping her to understand what was happening. Nonetheless, she was angry that she did not get the information before, as it felt like a lie to her.

2. Having an intersex sibling: experiences and misunderstandings

The previous section looked at the parental experiences of children with a variation in sex characteristics. There is quite a significant gap in the literature on the relationship between intersex people and their parents. Many intersex children also grow up with siblings. The experiences of siblings and the impact of medicalisation on sibling relationships are under-researched, and most of the existing work related to siblings of intersex children does so from a medical perspective, looking at hereditary traits of intersex variations and differences in the gender identity amongst children from the same family with the same intersex variation.

Our data highlights two trends. Sometimes siblings have access to more knowledge than the intersex person themselves and may act as a keeper of secrets. Secondly, the sibling may experience jealousy, misunderstandings and feeling left out. We will now discuss these situations based on the data we have gathered. We believe it would be interesting to look at ties between siblings or family members who share an intersex variation. However, we do not presently have any data on this matter. There are some insights to be found, perhaps, in movies and books by intersex people, such as the Australian documentary 'Orchids: my intersex adventure'[139] or the French autobiography by Emmanuelle Behloradsky and Elodie Lenoir 'Telle que tu me vois'[140]. In both cases, despite sharing the same variation as their respective sisters, the weight of the secrecy and shame was so strong that they never discussed it.

The sibling as the keeper of secrets

While the intersex variation may be taboo and rarely discussed, it happens that siblings, and sometimes even cousins, know more about it than the person themselves. They may have overheard discussions between parents or asked questions to their parents about the hospitalisation of their sibling. Parents sometimes disclose information while asking the sibling to keep it a secret. There is a possibility that they may sometimes use this information to bully or embarrass the intersex child. This can lead the intersex child to understand that they do not have all the information about their own body. For example, one person says:

> There is a sequence [in the movie Satyricon, by Fellini][141] where you see a hermaphrodite child locked in a golden cage and my sisters, who never really accepted me, turned to me, and said it should have been me in the golden cage. That was one of my biggest family shocks. (Interview 5, 17.02.2022, translated from French by the authors)

This situation created an imbalance, where the intersex child understands they do not have all the information or that other people have information on their situation, yet they themselves are not in a position where they feel as though they can ask. As in the above examples, when siblings hint towards the variation to their intersex sibling, it may be done crudely. The intersex person feels hurt but may not be able to grasp why, as they do not have the epistemic resources to understand. Following this statement, the participant continues by saying:

> Because they were very violent, and it is only now, as an adult, that I realise that they were minors too and that they suffered violence too... They spat out this violence, and it must have affected them for the rest of their lives too. They were victims of things that were said in the medical world; there were leaks... I did not know why they both turned around to tell me that I should have been in the cage. And there are many details like that when you put the story together; I think they were aware of some things… (Interview 5, 17.02.2022, translated from French by the authors)

Jealousy, incomprehension, and the feeling of being left out

The taboo surrounding an intersex variation may also affect the siblings. Some siblings may develop a level of jealousy. The medicalisation of the intersex child can take time and energy from the parents, making siblings feel left out. Similar experiences have been recorded amongst siblings of children with a disability, where they feel what they have to say is not

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[139] Hart, P. (Director) (2010). *Orchids: My intersex adventure* [Documentary].

[140] Behloradsky, E., & Lenoir, E. (2018). *Telle que tu me vois: L'Histoire d'une fille qui aurait dû être un garçon.* La Martinière.

[141] Fellini, F. (1969). *Satyricon.* PEA and Les artistes associés.

heard or valued[142]. The feeling of jealousy might be unsurprising, considering the level of unequal time and care that may be granted to an intersex child in some circumstances.

Furthermore, the explanations the child receives may contribute to feelings of jealousy. Sometimes lies are told to siblings to keep the secrets of surgeries and hospitalisations safe. This explanation can lead the endosex sibling to believe that they are being treated unfairly, which may result in a poor relationship with their sibling and lead to bullying at home.

3. School and beyond

The relationships with parents and siblings can influence future relationships with people for the intersex child in school and later as an adult in the workplace. It is important to note that parents may be advised by surgeons to allow their child to be operated on to reduce the risk of bullying. Parents may go to medical consultations with practical questions related to what they should tell the child's teachers or about how their child will be accepted at school. Answers that do not allow for non-surgical options may not be presented in medical settings. There is evidence to suggest that medical approaches may have contributed to worsening the mental health of children rather than reducing bullying or preventing dropping out[143].

Many intersex people report being excluded during their school years by their peers. This may be due to school absences related to hospital visits. Furthermore, the child may have other issues to deal with, such as mental health issues like anxiety, depression, and a feeling of not understanding what they are going through. While the purported purpose of medicalisation is acceptance by a child's peers, in practice, it may reduce social inclusion. Some intersex people report being excluded for not conforming to binary gender norms even when the child's identity is aligned with the sex they were assigned at birth. For intersex people whose gender identity does not correspond to the sex they were assigned at birth, these experiences of ostracism and not fitting in might be exacerbated.

The bullying intersex people experience may lead to the intersex child dropping out of school. Isolation and ostracism in school may impact the child's future relationships with members of the sex or sexes they find themselves attracted to in adulthood. Some intersex people report feeling left out when watching their friends begin dating in their teenage years. Stigma, shame, and secrecy around their body may make the thought of approaching a romantic interest prohibitive. Early formative experiences could therefore hamper opportunities for successful and satisfying romantic relationships in adulthood (you can read more about how intersex people navigate romantic relationships in Chapter 3). Some intersex people report being bullied as adults in the workplace and finding difficulty making connections and becoming friends with co-workers. Education and awareness related to intersex variations taught in schools in an age-appropriate manner may do much good in alleviating exclusion and bullying for intersex children.

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[142] Naylor, A., & Prescott, P. (2004). Invisible children? The need for support groups for siblings of disabled children. *British journal of special education*, 31(4), 199-206.

[143] Jones, T. (2016). The needs of students with intersex variations. *Sex Education*, 16(6), 602-618.

Medical snapshot

Healthcare for people with variations of sex characteristics by necessity includes parents as they care for their children. Parents can experience a range of psychosocial issues such as distress, and shame navigating relationships with siblings and broader family. There has been a shift in the care for children with variations of sex characteristics and their families toward psychosocial support provided for parents to address the concerns and issues parents might have. Family support significantly influences the body image, mental health and relationships people with sex characteristics have. As such, it has been recognised as the crucial part of the care provided by healthcare professionals, but has not been adequately implemented in the practice, leaving parental needs insufficiently met.

Legal snapshot

The Council of the European Union has affirmed that cultural, traditional, and religious values followed by the family of the intersex person cannot be used as a defence to justify any form of discrimination against the persons concerned[144]. It has been observed by the European bodies how when parents or legal guardians make decisions for medical intervention on the bodies of intersex children, they are made to make pressured decisions without being well-informed about the consequences of them[145] and this can be inherently problematic for the child[146]. The European Parliament has recommended State parties provide intersex individuals and their parents with adequate interdisciplinary counselling, support, and full information about the consequences of medical intervention[147]. The regional European bodies have also recommended States provide proper training to medical professionals to ensure the human rights of intersex people[148]. Not much research has been done by regional bodies on the experiences of intersex children in schools and how policies shall be developed in that respect. Nonetheless, in 2015, Malta developed the 'Trans, Gender Variant and Intersex Students in Schools Policy', which is a remarkable development towards ensuring protection and equality for intersex students[149].

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[144] Council of the European Union. (2013, June 23). *Guidelines to promote and protect the enjoyment of all human rights by lesbian, gay, bisexual, transgender and intersex (LGBTI) persons.* consilium.europa.eu/uedocs/cms_data/docs/pressdata/en/foraff/137584.pdf

[145] European Parliament. (2019, February 14). *Resolution 2018/2878 (RSP) of 14 Feb 2019 on the rights of intersex people OJ C 449/142.* https://eur-lex.europa.eu/legal-content/EN/TXT/?uri=CELEX%3A52019IP0128

[146] Office of the High Commissioner for Human Rights. (2019). *Human rights violations against intersex people: A background note. United Nations* 1, *15.* https://www.ohchr.org/en/documents/tools-and-resources/background-note-human-rights-violations-against-intersex-people; https://www.ohchr.org/sites/default/files/Documents/Issues/Discrimination/LGBT/BackgroundNoteHumanRightsViolationsagainstIntersexPeople.pdf

[147] European Parliament (2019, February 14). *op. cit.*; Council of Europe Parliamentary Assembly (2017, October 12). *Resolution 2191 (2017) on promoting the human rights of and eliminating discrimination against intersex people (adopted by the Assembly on 12 October 2017 (35th Sitting)) para 7.1.* https://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=24232

[148] Council of Europe parliamentary assembly (2013). *op. cit.;* European agency for fundamental rights (2015). *op. cit.*

[149] Ní Mhuirthile, T., Dixit, S., Zelayandía González, E., Lum, S., Mestre Martinez, Y. M., Aegerter, A., & Suess Schwend, A. (2022). *op. cit.*

Chapter 3: Reproduction and family building

Audrey Aegerter & Addy Berry

The previous two chapters have discussed the situation of intersex children. In the remainder of this eBook, we discuss the situation of intersex adults. In this chapter, we focus on family building and examine issues like intersex people creating family dealing with romantic relationships, infertility issues, stigma and troubles related to finding a partner.

1. Romantic relationships

Relationship and sex education in schools rarely, if ever, include bodies of people with intersex variations, so intersex people may leave school and enter adulthood with little information about their bodies, and may therefore be ill-equipped to form successful and satisfying romantic and sexual relationships. Additionally, the intersex person may carry feelings of stigma, secrecy, and shame from their childhood as well as the feelings of being different, inferior, or broken. Some intersex people fear rejection after finding out about their variation or variations. Some people felt confused about their sexual orientation after discovering they were intersex, as the following quotes from our research indicate:

> I didn't even know the word. I didn't even know the word (laughs). I knew I wasn't going to have children. I knew there was something different about me. I knew not that I had XY chromosomes. And I got the information that I was not a woman; I was a man. But at that time, when I got this information, I was already married. I was already a wife. (Interview 8, translated from German by the authors, 24.02.2022)
>
> I remember we were standing in front of the window, looking out; I remember this really... There were a lot of nice trees, we were looking out, and then he said: 'Daniela, you have XY chromosomes, but you should not tell your boyfriend because he won't understand' (Interview 27, 15.12.2022).

The two extracts show how the words used by the doctors can contribute, directly or indirectly, to the intersex person keeping their variation secret within the relationship.

Intersex men may face particular difficulties when finding a partner. Some intersex men, for example, might have no penis, or a small penis, because of their variation or because of surgical or hormonal interventions they have been subjected to in childhood. Heterosexual, cisgender intersex men, who learned only about penis-in-vagina penetrative sex may therefore feel at a loss due to the stigma and shame associated with penis size, dissuading them from attempting to have intimate relationships of any kind. Some heterosexual male cisgender intersex respondents reported difficulties in performing sexual intercourse, in part due to their variation, but also because of its surgical 'correction'. One respondent, when speaking about his sex life, uses the phrase 'sexual attempts'. For gay intersex men, the situation may also be complicated. Some gay intersex men feel they are not accepted by the gay community because of their bodies:

> In the gay scene, there is also a lot of discrimination... So, for inter persons... It's like this if you just don't look regular male in the genital area or also elsewhere, there is a lot of rejection… (Interview 12, translated from German by the authors, 6.4.2022)

> I have a somewhat peculiar homosexual background because I was looking for love, but by my biology and the operations I had... I was actually interested in boys, but the boys who were interested in boys were not interested in me because I was not really the type of boy. It was extremely painful because I felt rejected by the only world that interested me. (Interview 7, translated from French by the authors, 23.02.2022)

Intersex adults whose gender identities do not align with the sex they were assigned at birth may encounter transphobia, discrimination, rejection and even violence when navigating the dating scene. Those whose gender identities align with their assigned sex but whose bodies display traits commonly associated with a sex other than the one the intersex person was assigned to at birth, such as gynecomastia in men with Klinefelter syndrome or thick facial and body hair in women with Polycystic Ovarian Syndrome, may similarly face rejection or even transphobia when seeking romantic partners. For some intersex adults, their variation or the results of surgical interventions might cause traditional penetrative sex to be unpleasant, painful or impossible. For others, trauma related to early experiences, including medicalisation, may be a prohibitive factor when dating. Some intersex people find therapy helpful, as well as learning to think outside of the box regarding sex and romantic relationships by incorporating sex toys and finding partners in more accepting communities.

2. Reproduction and adoption

While some intersex people are fertile, many experience infertility due to their variation or surgeries such as gonadectomies. The discovery of infertility is how many intersex people assigned female at birth first hear about their variation. They may receive the information that they are 'normal' but 'just could not have a child'. As a result, many patient organisations for women with Mayer-Rokitansky-Küster-Hauser (MRKH) syndrome or Androgen Insensitivity Syndrome focus on reproduction. For instance, the French MRKH organisation is working closely with Maia, a surrogacy organisation, and a former member explains:

> In fact, it's that if you have MRKH syndrome, a priori, you have ovaries and not testicles. You have ovaries that can produce eggs. And so, if you puncture an egg and you organise an in vitro fertilisation, you can obtain embryos that can be placed in the uterus of another woman to have children that are 'yours' (said with a lot of irony). (Interview 4, translated from French by the authors, 16.02.2022)

Many books by intersex women focus on their experience and desire to adopt. This is, for example, the case with *Telle que tu me vois*[150], written by Emmanuelle Behloradsky and French CAIS activist Elodie Lenoir or *XOXY: A memoir*[151], written by intersex activist Kimberly Zieselman. In the first book, Elodie Lenoir writes extensively about her desire to become a mother. Kimberly Zieselman also writes about her journey of going through the adoption system in the USA and becoming a mother. Adoption may be an option for some, but factors

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[150] Behloradsky, E., & Lenoir, E. (2018). *op. cit*.

[151] Zieselman, K. M. (2020). *XOXY: A memoir (Intersex woman, mother, activist)*. Jessica Kingsley Publishers.

such as legal discrimination or a lack of legal protection in the intersex person's country may make adoption or even marriage impossible for them. Some intersex people may form 'families of choice', informally adopting others who have similarly faced rejection from family or community, which is a common practice in the LGBT+ community[152].

For some intersex people, in vitro fertilisation may provide opportunities to have children, but success is not guaranteed, and associated costs may be prohibitive. Similarly, sperm extracting procedures may be helpful for people with Klinefelter syndrome who may then try to have children, but again, success cannot be guaranteed.

Some intersex adults who are raising children may find living their truth complicated, clashing with their desire to not put their children at risk of discrimination.

> At the same time, I didn't want to be in the media too much, because I am a father. I have two daughters and two children at school... And I didn't want them to have problems at school because their father was on TV or in the press... So that held me back a lot. I thought to myself: I can't do this to my kids. If I do it when my children are grown up, that's up to me, but I don't want to do that now. (Interview 7, translated from French by the authors, 23.02.2022)

3. Logical family

Earlier in this chapter, we addressed some of the issues that intersex people may face when deciding to create a family of their own. Some intersex people, however, create or join a 'family of choice' or 'logical family' as a result of the shame, stigmatisation and violence that they may have faced in their childhood homes or throughout their lives. In his memoir, Armistead Maupin states that 'sooner or later, though, no matter where in the world we live, we must join the diaspora, venturing beyond our biological family to find our logical one, the one that actually makes sense for us. We have to, if we are to live without squandering our lives'[153]. The concept of logical family is relevant to the study of intersex people. Some intersex people report having been expelled from their religious communities or made to feel less welcome either because they are intersex or because of reasons related to their variation, such as difficulty getting married or having children. Intersex people, if able, may flee their family home and surroundings in search of acceptance and community elsewhere, possibly allowing opportunities for the formation of friendships and satisfying sexual as well as romantic relationships that may not have been possible in the area in which they grew up, perhaps especially if they come from an isolated, rural, or conservative community. The remainder of this chapter is dedicated to how intersex people access non-biological family structures, such as intersex activist organisations, peer-support groups, or patient groups, after suffering a disconnect from their biological family. It also highlights the repercussions of the logical family on the person's well-being and identity.

Some intersex people find love amongst the queer community, for example, where there is often a broader understanding and acceptance of bodily variations and what it means to

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[152] Dakin, E. K., Williams, K. A., & MacNamara, M. A. (2020). Social support and social networks among LGBT older adults in rural southern Appalachia. *Journal of gerontological social work*, *63*(8), 768-789.

[153] Maupin, A. (2017). *Logical family: A memoir*. Random House.

engage in sexual relationships, allowing for more opportunities to tailor and adapt sexual activities to the body and genitalia of the intersex person and their prospective partner or partners. Some intersex people, however, encounter rejection and hostility even within the LGBT+ community, often owing to a lack of understanding and knowledge related to intersex variations such as confusion and conflation of transgender and intersex.

Some intersex people report finding the connection they lack with biological family amongst the intersex community, where despite differences in variations they find they have very much in common. Many intersex people say that amongst other intersex people, they find many conversations do not need to be had, which brings a sense of relief. Intersex people sometimes talk about building community through their activism work, or through local art or drama groups for example. Some heterosexual, cisgender intersex men may find difficulty fitting in at intersex gatherings where the participants are mostly women, preferring the company of other men like themselves. However, they may face difficulties finding other men like themselves to form a community with because of social pressures and stigma related to penis size, for example, within a masculine hegemonic society.

Stigma, secrecy, shame, and a lack of awareness around intersex existence create barriers for the forming of intersex ‘logical family’ and community. Medical dishonesty and policy that recommends hiding medical histories from intersex people work to make the forming of a family, ‘logical’ or otherwise, difficult. Intersex people often report asking their medical providers to be put in touch with other intersex people only to be told their variation is so rare that they would never meet anyone else like them, or to have their request denied or ignored.

Medical snapshot
People with variations of sex characteristics have lower chances than the general population to have children, however, intersex reproduction has been a side-lined topic in care for a very long time. Healthcare professionals have also conveyed information about infertility in a negative way that has worsened relationships between children with VSC and their parents. With the improvement of the fertilization techniques and improved prognosis for fertility in people with variations of sex characteristics, there are now better chances that people with variations of sex characteristics can have babies if they wish to do so. But (psychosocial) care for people with variations of sex characteristics should also address adoption as a viable option for those who want to build a family but cannot have children due to infertility or simply because they do not want to have biological children.

Legal snapshot
In the legal sphere, concerns relating to fertility and adoption for intersex people have still not been raised. The international and regional bodies have not made any recommendations regarding fertilisation techniques and adoption. Further, none of the countries have taken the initiative to make laws in this area of intersex rights. Even regarding civil partnerships and relationships, the development made is liminal. The Council of Europe Parliamentary Assembly in its 2017 Resolution has agreed that 'with regard to civil status and legal gender recognition… ensure that, in accordance with the right to respect for private life, intersex people are not prevented from entering into a civil partnership or marriage or from remaining in such a partnership or marriage as a result of the legal recognition of their gender'[154]. The concern has not been raised again in any document, recommendation, or resolution.

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[154] Council of Europe Parliamentary Assembly. (2017, October 12). *op. cit.*

Chapter 4: Ageing and intersex

Addy Berry

This chapter examines life for older intersex people, including challenges they might face such as isolation and problems accessing adequate and appropriate healthcare. Quality of life and factors that contribute to both negative and positive outcomes will be looked at. Intersex joy for older people will be explored along with methods that older intersex people might use to express themselves. The chapter is based on literature work carried out as part of a research project[155] and on research data from the study of older intersex people in Europe.

1. Quality of life

This section looks at quality of life for older intersex people and how decisions made early in the intersex child's life can negatively impact later outcomes. Acceptance by one's own family can be an important factor in the building of self-esteem and self-efficacy in a child[156]. However, some older intersex people report having felt like a misfit in their family growing up, being treated differently than their siblings. There is a dearth of literature on intersex experience, which some projects from INIA[157] hope at least in part to address, however, recent literature shows increased depression and suicidality amongst transgender youth experiencing parental and sibling rejection[158]. Some older intersex people have said that they were considered a curse on their family, being blamed for everything that went wrong. Being treated as an outsider within the family home during one's formative years can lead to a person feeling like an outsider for much of their lives in addition to a higher likelihood of being affected by a plethora of health issues such as mental health and heart problems[159,160]. This can negatively affect a person's ability to establish relationships with other people and succeed in the world[161]. Again, there is a paucity of literature on parent support and intersex outcomes, however, transgender literature suggests that education and support for parents of intersex children could benefit later outcomes for the intersex child[162].

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[155] INIA. (n.d). *op. cit.;* Berry, A. & Monro, S. (2022). *op. cit.;* Crocetti, D., Berry, A., & Monro, S. (2023). *op. cit.*

[156] Meanley, S., Flores, D. D., Listerud, L., Chang, C. J., Feinstein, B. A., & Watson, R. J. (2021). The interplay of familial warmth and LGBTQ+ specific family rejection on LGBTQ+ adolescents' self-esteem. *Journal of adolescence*, 93, 40-52.

[157] INIA. (n.d). *op. cit*

[158] Bosse, J. D., Clark, K. D., Dion, K. A., & Chiodo, L. M. (2023). Transgender and nonbinary young adults' depression and suicidality is associated with sibling and parental acceptance-rejection. *Journal of nursing scholarship*.

[159] Lacey, R. E., Kumari, M., & Bartley, M. (2014). Social isolation in childhood and adult inflammation: evidence from the National Child Development Study. *Psychoneuroendocrinology*, 50, 85-94.

[160] Stingeni, L., Belloni Fortina, A., Baiardini, I., Hansel, K., Moretti, D., & Cipriani, F. (2021). Atopic dermatitis and patient perspectives: insights of bullying at school and career discrimination at work. *Journal of asthma and allergy*, 919-928.

[161] Strøm, I. F., Aakvaag, H. F., Birkeland, M. S., Felix, E., & Thoresen, S. (2018). The mediating role of shame in the relationship between childhood bullying victimization and adult psychosocial adjustment. *European journal of psychotraumatology*, 9(1), 1418570.

[162] Simons, L., Schrager, S. M., Clark, L. F., Belzer, M., & Olson, J. (2013). Parental support and mental health among transgender adolescents. *Journal of adolescent health*, 53(6), 791-793.

Many intersex people report having been bullied in school with some dropping out, having negative repercussions for financial security in later life. There are specific issues faced by young people with some variations, for example undiagnosed and untreated Klinefelter syndrome can leave a child struggling with shyness, negative self-image, learning difficulties[163] and bullying[164]. Early testing for Klinefelter syndrome[165] and inclusion of intersex variations in educational curriculums could contribute to acceptance[166] and therefore perhaps more positive outcomes in later life for older intersex people.

People with an intersex variation often claim to be struggling both physically and mentally because of the effects of early medical interventions and associated traumas which can negatively impact their quality of life[167]. Ending early procedures such as clitoral reduction surgery and gonadectomies until the intersex person is old enough to make an informed decision for themselves and instead furthering awareness and acceptance of bodily variations amongst the public should positively impact later outcomes and quality of life for intersex people[168]. Intersex people that are transgender may face additional employment and housing discrimination[169]. Pausing irreversible surgeries and hormonal procedures until the intersex person is old enough to express who they are should reduce the number of older intersex people battling transphobic discrimination in the future.

Good health is a marker of life quality. However, for the many older intersex people struggling with physical problems resulting from early procedures, it is important that they receive adequate, appropriate, and timely medical treatment to facilitate an improvement of quality of life. This means that more education is needed for medical providers tasked with their care[170]. This education should be based on and influenced by lived experience rather than theory. Quality of life for future older intersex people can be improved by addressing issues with intersex beginnings through education and awareness[171]. This could in turn address

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[163] Skakkebæk, A., Wallentin, M., & Gravholt, C. H. (2021). Klinefelter syndrome or testicular dysgenesis: genetics, endocrinology, and neuropsychology. *Handbook of clinical neurology*, 181, 445-462.

[164] Yaseen, K., Fazil, H., & Hashmi, R. (2020). Barriers perceived by teachers in the education of individuals with Klinefelter syndrome (transgender). *Journal of educational sciences*, *7*(2), 37-48.

[165] Samango-Sprouse, C. A., Counts, D. R., Tran, S. L., Lasutschinkow, P. C., Porter, G. F., & Gropman, A. L. (2019). Update on the clinical perspectives and care of the child with 47, XXY (Klinefelter syndrome). *The application of clinical genetics*, 191-202.

[166] Brömdal, A., Zavros-Orr, A., Lisahunter, Hand, K., & Hart, B. (2021). *op. cit.*

[167] Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., Zieselman, K., & Flatt, J. D. (2020). *op. cit.*

[168] Berry, A. W., & Monro, S. (2022). *op. cit.;* Crocetti, D., Arfini, E. A., Monro, S., & Yeadon-Lee, T. (2020). 'You're basically calling doctors torturers': stakeholder framing issues around naming intersex rights claims as human rights abuses. *Sociology of health & illness*, 42(4), 943-958; Bauer, M., Truffer, D., & Crocetti, D. (2020). Intersex human rights. *The international journal of human rights*, 24(6), 724-749.

[169] Granberg, M., Andersson, P. A., & Ahmed, A. (2020). Hiring discrimination against transgender people: Evidence from a field experiment. *Labour economics*, *65*, 101860; Glick, J. L., Lopez, A., Pollock, M., & Theall, K. P. (2019). "Housing insecurity seems to almost go hand in hand with being trans": Housing stress among transgender and gender non-conforming individuals in New Orleans. *Journal of urban health*, 96, 751-759.

[170] Ussher, J. M., Perz, J., Allison, K., Power, R., Hawkey, A., Dowsett, G. W., ... & Anazodo, A. (2022). Attitudes, knowledge and practice behaviours of oncology health care professionals towards lesbian, gay, bisexual, transgender, queer and intersex (LGBTQI) patients and their carers: A mixed-methods study. *Patient education and counseling*, 105(7), 2512-2523.

[171] Brömdal, A., Zavros-Orr, A., Lisahunter, Hand, K., & Hart, B. (2021). *op. cit.*

problems faced by future older intersex people such as the paucity of knowledgeable care providers and even may lead to a cessation on early medical procedures that leave intersex people struggling throughout their lives.

2. Isolation

Many intersex people experience heightened isolation in old age[172]. Rejection by family due to shame and secrecy can be a contributing factor as well as lifelong fractures in relationships with siblings stemming from secrecy and misconceptions surrounding the intersex person's variation in childhood[173]. For others, infertility related to either their variation or early medical procedures such as gonadectomies can contribute to intersex people being isolated in later life[174].

Stigma, shame and societal norms around sex and gender can result in intersex people being rejected from communities they are born into, such as religious communities, and not being accepted into other communities[175]. These prejudices can affect dating prospects also, as discussed earlier in this eBook[176]. Transphobia can increase isolation for older intersex people that are also transgender[177]. As mentioned above, traits like shyness associated with variations such as Klinefelter syndrome making the act of making friends difficult[178]. Experiences of bullying and ostracisation in childhood can carry into later life leading to workplace bullying in adulthood[179]. All of these factors can combine to exacerbate loneliness and isolation for intersex people in their final years.

Older intersex people can find community amongst other intersex people and through intersex organisations that host regular meet ups either in real life or through the internet. Intersex people who struggle throughout their lives without learning about their variation or intersex community may be deprived of such opportunities[180]. Those that live in isolated areas, or those that have difficulty accessing the internet, may face increased isolation as well as trouble availing of online community spaces. Barriers to community include dishonesty in medical settings such as doctors telling intersex people that their variation is so rare that they will never meet anyone else like them or telling parents of intersex children to keep their child's variation secret from friends and family as well as their intersex child themselves[181]. Many early medical procedures serve to hide evidence of intersex variations. These actions

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[172] Jones, C. (2022). The harms of medicalisation: intersex, loneliness and abandonment. *Feminist theory*, 23(1), 39-60.

[173] Meanley, S., Flores, D. D., Listerud, L., Chang, C. J., Feinstein, B. A., & Watson, R. J. (2021). *op. cit. ;* Bosse, J. D., Clark, K. D., Dion, K. A., & Chiodo, L. M. (2023). *op. cit.*

[174] Jones, C. (2020). Intersex, infertility and the future: Early diagnoses and the imagined life course. *Sociology of health & illness*, 42(1), 143-156.

[175] Dakin, E. K., Williams, K. A., & MacNamara, M. A. (2020). *op. cit.*

[176] Petersen, J. K. (2021). *op. cit.*

[177] Hajek, A., König, H. H., Blessmann, M., & Grupp, K. (2023, May). Loneliness and social isolation among transgender and gender diverse people. *Healthcare*, 11 (10) p. 1517.

[178] Fabrazzo, M. (2020). Klinefelter syndrome: From a disabling condition to a variant of normalcy: Neuropsychiatric aspects. *Klinefelter's Syndrome: From a Disabling Condition to a Variant of Normalcy*, 77-83.

[179] Stingeni, L., Belloni Fortina, A., Baiardini, I., Hansel, K., Moretti, D., & Cipriani, F. (2021). *op. cit.*

[180] Jones, C. (2022). *Op. cit.*

[181] Jones, C. (2022). *Op. cit.*

exacerbate silence, stigma, and a paucity of intersex awareness amongst the general public[182]. Increased intersex awareness for the public, medical professionals and for intersex people themselves could greatly reduce isolation in later life future generations of older intersex people.

3. Health and healthcare

Here I look at the intersection of an increasing need for, and dependency on, healthcare for ageing intersex people and barriers to accessing adequate and appropriate care. Suffering multiple early negative experiences in healthcare settings can be expected to have a detrimental effect on a person's trust in the medical establishment[183]. Although many early procedures are performed for the purported benefit of the intersex person, these surgical and hormonal interventions can leave the person struggling with lifelong physical and mental and physical difficulties[184]. Many older intersex people report having difficulty throughout their lives with finding help in medical settings to alleviate issues stemming from procedures they were subjected to as children[185]. This too can damage faith in the medical establishment as a place to find help when needed, even if it is for issues unrelated to intersex matters. For some, memories of being abandoned at a hospital as children and made to undergo surgeries without having had anything explained to them leads to the intersex person having traumatic associations with hospitals and other medical settings[186]. Early experiences of objectification, such as being examined by groups of medical students without the child's consent, or without having anything explained to them, are recalled by many older intersex adults as particularly traumatic[187]. Others reported being treated with disrespect, and even revulsion, in adulthood by doctors and nurses upon disclosing their intersex variation when seeking care. Many have spoken about finding a lack of knowledge related to their variation amongst medical professionals that is often accompanied by a lack of respect for, and dismissal of, the lived experience of the intersex person. Older intersex people have reported avoiding contact with doctors when in need of medical care and not showing up for scheduled tests because they doubted the intentions of their doctor[188]. As we age, our dependency on medical care providers increases, so it is of the utmost importance that older intersex people can seek help and receive adequate care in confidence. In addition to common health issues associated with ageing, many older intersex people have additional health needs, sometimes stemming from early medical interventions, such as osteopenia and osteoporosis, or urinary pain, discomfort, and difficulties[189]. For intersex people that are also transgender, they may also struggle to

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[182] Jones, C. (2022). *op. cit.*

[183] Daines, C. L., Hansen, D., Novilla, M. L. B., & Crandall, A. (2021). Effects of positive and negative childhood experiences on adult family health. *BMC public health*, 21, 1-8.

[184] Bauer, M., Truffer, D., & Crocetti, D. (2020). *Op. cit. ;* Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., Zieselman, K., & Flatt, J. D. (2020). *op. cit.*

[185] Crocetti, D., Berry, A., & Monro, S. (2023). *op. cit.*

[186] Wang, J. C., Dalke, K. B., Nachnani, R., Baratz, A. B., & Flatt, J. D. (2023). Medical mistrust mediates the relationship between nonconsensual intersex surgery and healthcare avoidance among intersex adults. *Annals of behavioral medicine*, kaad047.

[187] Wang, J. C., Dalke, K. B., Nachnani, R., Baratz, A. B., & Flatt, J. D. (2023). *op. cit. ;* Bauer, M., Truffer, D., & Crocetti, D. (2020). *op. cit.*

[188] Wang, J. C., Dalke, K. B., Nachnani, R., Baratz, A. B., & Flatt, J. D. (2023). *op. cit.*

[189] Crocetti, D., Monro, S., Vecchietti, V., & Yeadon-Lee, T. (2021). *op. cit.*

access adequate transgender healthcare and may suffer transphobic abuse and discrimination in healthcare settings[190].

Comprehensive education for medical students could do much to resolve many of the issues faced by intersex people in need of care[191]. This training should be guided by the lived experiences of intersex people and could look at ways of interacting that do not contribute to distrust and build on trauma from previous experiences in medical settings[192]. A medical establishment with respect for intersex lived experiences may be more likely to re-examine the reasons many early medical interventions are performed on intersex children leading to better outcomes for intersex people.

4. Mental health and coping

While some older intersex people say that finding a good therapist has been both lifechanging and lifesaving for them, many talk about how difficult it can be to find a mental health professional that is adequately versed in intersex issues and capable of providing the necessary help. While more research is needed, there is evidence that intersex adults suffer from much worse mental health than non-intersex people[193]. These issues may stem from family rejection, societal ostracisation, or be associated with the intersex person's early medical experiences[194]. Rates of attempted suicide are much higher amongst intersex people than amongst the general public[195]. LGBTQ+ groups including Intersex people have reported high rates of alcohol and drug abuse as well as self-harming behaviour[196]. It is not uncommon for surgeons and endocrinologists to recommend that intersex people be referred to mental health professionals, especially when medical options for remedy are not available or advisable. Additionally, many intersex people have spoken about having symptoms related to either their variation or medical treatment dismissed by doctors as mental health issues[197]. However, some older intersex people say that poor experiences when receiving therapy and a lack of available therapists adequately versed in intersex issues can act as a deterrent to seeking therapy when needed[198]. Education for mental health professionals directed by the lived experience of intersex people could help address this paucity of knowledge, as would

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[190] Cicero, E. C., Reisner, S. L., Silva, S. G., Merwin, E. I., & Humphreys, J. C. (2019). Healthcare experiences of transgender adults: An integrated mixed research literature review. *ANS. Advances in nursing science*, 42(2), 123.

[191] Zeeman, L., & Aranda, K. (2020). A systematic review of the health and healthcare inequalities for people with intersex variance. *International journal of environmental research and public health*, 17(18), 6533.

[192] Wang, J. C., Dalke, K. B., Nachnani, R., Baratz, A. B., & Flatt, J. D. (2023). *op. cit.*

[193] Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., Zieselman, K., & Flatt, J. D. (2020). *op. cit.*

[194] Wang, J. C., Dalke, K. B., Nachnani, R., Baratz, A. B., & Flatt, J. D. (2023). *Op. cit. ;* Meanley, S., Flores, D. D., Listerud, L., Chang, C. J., Feinstein, B. A., & Watson, R. J. (2021). *Op. cit ;* Bosse, J. D., Clark, K. D., Dion, K. A., & Chiodo, L. M. (2023). *op. cit.*

[195] Rosenwohl-Mack, A., Tamar-Mattis, S., Baratz, A. B., Dalke, K. B., Ittelson, A., Zieselman, K., & Flatt, J. D. (2020). *op. cit.*

[196] Zeeman, L., & Aranda, K. (2020). *op. cit.;* Meads, C., Zeeman, L., Sherriff, N., & Aranda, K. (2023). Prevalence of alcohol use amongst sexual and gender minority (LGBTQ+) communities in the UK: a systematic scoping review. *Alcohol and alcoholism*, agad029.

[197] Sebring, J. C. (2021). Towards a sociological understanding of medical gaslighting in western health care. *Sociology of health & illness*, 43(9), 1951-1964.

[198] Berry, A. W., & Monro, S. (2022). *op. cit.*

greater awareness amongst the general population. Introducing intersex education into relationship and sexual education curriculums in school as is age appropriate could help to ensure that future therapists as well as medical practitioners already have some intersex awareness before embarking on their chosen career path[199].

Some older intersex people have spoken about how embracing the arts has helped them learn to express themselves and cope with their trauma and mental health issues, especially in the absence of accessible and adequate mental healthcare. Some older intersex people have learned or taught themselves to paint and sculpt. Others are published and accomplished writers, while others still have found that expressing themselves through theatre or music performance has been beneficial to their mental health and increased their social circle.

5. Eldercare

Many older people become reliant upon eldercare in their final years. This prospect might be anxiety inducing even in the most ideal circumstances, but for older intersex people that carry feelings of shame related to their own bodies, this anxiety may be heightened. Many older intersex people express great fear at the thought of becoming dependent in later life.

These anxieties might be related to their traumatic associations with care settings, their experiences of poor or hostile care throughout their lives, or to what the reaction of carers might be upon seeing them naked. As many eldercare facilities are run by religious institutions, older intersex people who suffered during their formative years either in a religious family home, a religious school or some other religious institution may find this problematic[200].

As previously discussed, many older intersex people suffer from heightened isolation, meaning they may be less likely to receive visits from family and friends at the care home in which they reside. Some may fear parting with accepting community they have built. Others may fear disclosing closely guarded secrets about themselves and their anatomy with the onset of dementia. Intersex people who suffered bullying throughout their lives because their bodies or behaviour did not conform to societal gender norms may fear bullying for these same reasons from staff and other residents. Intersex people that happen to be transgender may harbour fears of experiencing transphobia and transphobic violence while in a care setting with no way of seeking help[201]. Gay, lesbian and bisexual older intersex people may have fears related to homophobic and biphobic abuse[202]. If an older intersex person has no visitors at their care facility, this means there will be reduced opportunities for them to report deficiencies in their care or abuses they might be suffering. Some older intersex people have expressed their intention to commit suicide in advance of their becoming care dependent. Switzerland has taken measures to address concerns such as those mentioned above by

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[199] Brömdal, A., Zavros-Orr, A., Lisahunter, Hand, K., & Hart, B. (2021). *op. cit.*

[200] Latham, J. R., & Barrett, C. (2015). *op. cit.*

[201] Bloemen, E. M., Rosen, T., LoFaso, V. M., Lasky, A., Church, S., Hall, P., ... & Clark, S. (2019). Lesbian, gay, bisexual, and transgender older adults' experiences with elder abuse and neglect. *Journal of the American geriatrics society, 67(*11), 2338-2345.

[202] Bloemen, E. M., Rosen, T., LoFaso, V. M., Lasky, A., Church, S., Hall, P., ... & Clark, S. (2019). *op. cit.*

working to open care homes for its older LGBTI citizens in addition to providing specialised training and certification for homes that would like to be intersex inclusive[203].

Medical snapshot
Care for people with variations of sex characteristics is primarily organised around and directed towards the paediatric department. In most care centres, the needs of adult people with variations of sex characteristics are not met, because there are not enough adult specialists, or the existing ones do not have the knowledge and expertise to provide care for adults with variations of sex characteristics. Mental health issues remain particularly unaddressed as there are not enough resources and attention given to difficulties faced by adults subjected to non-consensual, invasive, irreversible and medically unnecessary interventions in childhood. These are needs in the provision of care for adult people with variations of sex characteristics that demand urgent attention.

Legal snapshot
The current legal system does not have any provision for protection of older intersex people. Most of the human rights laws for intersex people revolve around anti-discrimination and early medical intervention. Issues raised in this chapter, like isolation, access to adequate and appropriate healthcare, mental health and coping specifically for elder intersex people have not yet been raised and remedied in the legal sector. The European Court of Human Rights (ECtHR) has interpreted Article 2 and Article 8, and in limited circumstances Article 3 of the European Convention for the Protection of Human Rights and Fundamental Freedoms (ECHR), however, as obligation to preserve the health, life, and well-being of any individual[204]. Furthermore, Principles 17 and 18 of the Yogyakarta Principles Plus advocate for the right of any person to have the highest attainable standard of health and protection from medical abuses[205]. Regarding mental well-being, the Third International Intersex Forum has demanded that intersex people and their parents/care providers have accessibility to autonomous, non-pathologising psycho-social and peer support throughout their lives[206]. The only State to incorporate a legal provision in support of the mental health of elder intersex people is Malta[207].

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[203] Swissinfo. (2020, July 12). *op. cit.*

[204] Arskaya v. Ukraine, Application no. 45076/05; Vavřička and Others v. the Czech Republic [GC] Applications nos. 47621/13 and 5 others. At para 282; Paposhvili v Belgium (Application no. 41738/10). At paras 174-175

[205] Yogyakarta Principles plus 10, Principle 17 and 18, http://yogyakartaprinciples.org/wp-content/uploads/2017/11/A5_yogyakartaWEB-2.pdf

[206] Oii Europe. (2013, December 1). Participants in the third international intersex forum, Malta. https://oiieurope.org/malta-declaration/

[207] Government of Malta. (2015, April 14). *Gender identity, gender expression and sex characteristics act, Section 15.* https://tgeu.org/wp-content/uploads/2014/02/Malta_GIGESC_2015.pdf

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