ADMINISTRATION FOR EAGILIES

IM#: ACF-IOAS-IM-25-01

DATE: January 16, 2025

- **TO:** State, territorial, tribal, and local policymakers and administrators of systems, agencies, and programs responsible for children, youth, and family health and well-being
- **SUBJECT:** Improving Services and Outcomes for Intersex Children and Adolescents and their Families

BACKGROUND

The over five million intersex people in the United States deserve to live happy and fulfilling lives free from stigma and discrimination. However, intersex children, adolescents, and adults can experience significant distress if their intersex variations are treated as problematic and shameful by others. Parents and caregivers of intersex children also often struggle with isolation, stigma, and conflicting, incomplete, or inaccurate information regarding their child's variation, needs, and future development.¹ ACF programs can enhance the well-being and outcomes of intersex children, youth, and their parents by providing supportive, non-stigmatizing environments and facilitating access to family support, peer support, and accurate information.²

ACF programs can carry out many promising practices to improve the lives and well-being of intersex children and their parents and caregivers. Programs can offer training to grantees, staff, contractors, and providers to help them welcome and accept intersex people and acknowledge their unique needs, can facilitate access to accurate information, and can refer intersex people to supportive services including peer support, affirming mental health supports, and connection with intersex-affirming organizations. Where such supports are not available locally, ACF programs can refer intersex clients and their parents and caregivers to national and online resources.³

Intersex variations, which occur in approximately 1.7% of people, are a natural component of human diversity. Intersex is an umbrella term for people born with variations in sex characteristics or reproductive anatomy. Sex characteristics refer to physical traits which are

https://www.hrw.org/sites/default/files/report_pdf/lgbtintersex0717_web_0.pdf

¹ Human Rights Watch. (2017). "I want to be like nature made me": Medically unnecessary surgeries on intersex children in the U.S. Human Rights Watch.

² See footnotes 11-13 below.

³ See resources section below.

present from birth (chromosomes, gonads, external genital and structures, sex hormone production and response) or develop during puberty (secondary sex characteristics). A child's intersex variation may be identified at birth, during puberty, or at any later time; adults may discover they have intersex traits while seeking fertility or other medical care.

The term intersex is not synonymous with transgender or nonbinary. Like any child or youth, intersex children or youth may have any gender identity; they may self-identify as male, female, or nonbinary.

INSTRUCTION / GUIDANCE

ACF programs can reduce distress and stigma for intersex children and youth by promoting supportive, non-stigmatizing environments and facilitating access to supports including family support, peer support, age-appropriate information, and psychosocial support.

Family acceptance and social support have been shown to improve mental health outcomes for intersex people. Supporting parents with information and resources about intersex variation is important for family acceptance. Parental acceptance of a child's intersex variation can significantly reduce the risk of mental health distress and suicidal ideation among intersex children.⁴ Similarly, peer support, including through intersex support groups and community organizations, can significantly improve mental health outcomes and build mental health resilience.⁵

Multiple recent studies have illustrated that openness about intersex variation can result in more positive psychological outcomes, including reduced depression, feelings of shame, and isolation.⁶ A survey of 272 intersex people demonstrated that the acceptance of intersex variation significantly impacts family dynamics, and intersex participants wanted their families to embrace them for who they are, provide more information on their variations, and help them to access affirming care.⁷

⁴ Schweizer, K., Brunner, F., Gedrose, B., Handford, C., & Richter-Appelt, H. (2016). Coping with diverse sex development: Treatment experiences and psychosocial support during childhood and adolescence and adult wellbeing. *Journal of Pediatric Psychology*, *41*(5), 530–539. <u>https://doi.org/10.1093/jpepsy/jsw058</u>

⁵ Ibid. See also Henningham, M., & Jones, T. (2021). Intersex students, sex-based relational learning & isolation. *Sex Education*, 21(5), 600–613. <u>https://doi.org/10.1080/14681811.2021.1873123</u> and Jones, T. (2016). The needs of students with intersex variations. *Sex Education*, 16(6), 602–618. <u>https://doi.org/10.1080/14681811.2016.1149808</u> ⁶ See Davis, G., & Wakefield, C. (2017). The intersex kids are all right? Diagnosis disclosure and the experiences of intersex youth. In P. Neff Claster, S. Lee Blair, & L. E. Bass (Eds.), *Sociological studies of children and youth* (Vol. 23, pp. 43–65). Emerald Publishing Limited. <u>https://doi.org/10.1108/S1537-466120170000023004</u>; van de Grift, T. C. & on behalf of dsd-LIFE. (2021). Condition openness is associated with better mental health in individuals with an intersex/differences of sex development condition: Structural equation modeling of European multicenter data. *Psychological Medicine*, 1–12. <u>https://doi.org/10.1017/S0033291721004001</u>; B. Hart, & Shakespeare-Finch, J. (2022). Intersex lived experience: Trauma and posttraumatic growth in narratives. *Psychology & Sexuality*, 13(4), 912–930. https://doi.org/10.1080/19419899.2021.1938189

⁷ Jones, T. (2017). Intersex and families: Supporting family members with intersex variations. *Journal of Family Strengths*, 17(2), 8.

A lack of accurate information and psychosocial support can create extraordinary stress and uncertainty for expectant and new parents of intersex children.⁸ ACF programs can ensure that parents of intersex children are aware of the availability of information about intersex variations, can facilitate access to peer support and psychosocial support, and can help parents and caregivers address barriers to providing an affirming, supportive environment for their child.

In addition to the specific recommendations outlined below in the sections on serving intersex children and adolescents and their parents, ACF recommends that programs partner with trusted intersex-affirming community-based and national organizations and include people with lived intersex experience in every effort to implement these recommendations. Attentiveness to the experiences, traumas, and successes of individuals with diverse lived intersex experiences is essential throughout the process to develop and implement comprehensive intersex-affirming practices.

Services and supports for intersex children, including infants and young children.

All ACF program offices and funding recipients working with intersex children, including infants and young children, should consider and address the needs a child or youth may have as a result of their intersex variation, including relevant social and learning needs.⁹

ACF program offices and recipients should assess their policies, programs, and training to ensure they are providing adequate support and information to agency and program staff and parents, caregivers, and providers, to offer a supportive environment for every child, including intersex children.¹⁰

When considering any out of home placement such as a foster care or shelter placement, including one for an intersex child or youth, program offices and recipients must consider whether the prospective environment will be safe and appropriate and in the best interest of the child. This includes that the child or youth's whole development will be supported in the placement that the agency determines is most appropriate for the child or youth. For intersex children, such placements should be with providers who are supportive and affirming of the intersex child, and who can provide the child with relevant information, peer support, and other resources related to their intersex variations and avoid stigmatizing or shaming the child due to these variations.

Services and supports for intersex adolescents and young adults.

ACF program offices and recipients working with adolescents and young adults should offer services and supports that complement each youth or young adult, including an intersex youth or young adult, in their own efforts to achieve self-sufficiency and to embrace responsibility for

⁸ Charron, M., Saulnier, K., Palmour, N., Gallois, H., & Joly, Y. (2022). Intersex stigma and discrimination: Effects on patient-centred care and medical communication. *Canadian Journal of Bioethics*, 5(2), 16.

https://doi.org/10.7202/1089782ar; see also Pasterski, V., Mastroyannopoulou, K., Wright, D., Zucker, K. J., & Hughes, I. A. (2014). Predictors of posttraumatic stress in parents of children diagnosed with a disorder of sex development. *Archives of Sexual Behavior, 43*(2), 369–375. <u>https://doi.org/10.1007/s10508-013-0196-8</u> and Rolston, A. M., Gardner, M., Vilain, E., & Sandberg, D. E. (2015). Parental reports of stigma associated with child's disorder of sex development. *International Journal of Endocrinology, 2015*, 1–15. <u>https://doi.org/10.1155/2015/980121</u>

⁹ See resources section below and footnotes 11-13.

¹⁰ See resources section below.

transitioning from adolescence to adulthood. As appropriate or requested, this may include services or supports to assist intersex youth or young adults in increasing their readiness and competence to understand and articulate their own values and needs, develop healthy relationships,¹¹ cultivate personal resilience,¹² and explore any issues or concerns related to gender identity or expression, sexual orientation, body image, or experiences of trauma, bias, or discrimination.

As appropriate or requested, recipients should also support intersex youth and young adults to access opportunities such as mentoring programs, peer support groups, or other community activities that affirm and support their identities in an age-appropriate manner. For example, a recipient could support a youth or young adult who wishes to participate in a Gender and Sexualities Alliance club within their high school or participate in an intersex support group.

Services and supports for parents, caregivers, and potential parents and caregivers.

All ACF program offices and recipients should consider what types of practices and services would best support parents and caregivers of intersex children, as well as other agency and program staff, contractors, and providers working with these caregivers. As noted above, parents and caregivers of intersex children often struggle with isolation, stigma, and conflicting, incomplete, or inaccurate information regarding their child's intersex variation and future development, which can create barriers for parents and caregivers to providing an affirming, supportive environment for their child.

Agencies should consider what types of practices and services would best support families to understand and accept their intersex child,¹³ to address any experiences of social or cultural stigma, and to access social support and connection for parents, the child, or other family members, including connecting with other families or intersex youth, adults, or community groups.

ADDITIONAL RESOURCES

Resources for intersex children and youth and their families

- interACT. (n.d.). *interConnect: A community for intersex people*. <u>https://interconnect.support/</u>
- New York City Department of Health and Mental Hygiene. (n.d.). *Intersex health*. NYC Health. <u>https://www.nyc.gov/site/doh/health/health-topics/intersex-health.page</u>
- interACT Advocates for Intersex Youth. (n.d.). *Intersex brochures*. <u>https://interactadvocates.org/intersex-brochures/</u>

¹¹ See, e.g., Marinus, M. A., & Cense, M. A. (2024). A life course perspective on the sexual development of young intersex people. *Healthcare*, *12*(1), 239. <u>https://pubmed.ncbi.nlm.nih.gov/38255126/</u>

¹² See, e.g., van de Grift, T. C., et al. (2024). Minority stress and resilience experiences in adolescents and young adults with intersex variations/differences of sex development. *Psychology of Sexual Orientation and Gender Diversity, Advance online publication*. <u>https://psycnet.apa.org/fulltext/2024-51548-001.html</u>

¹³ See the resource section below including Astle, S., et al. (2024). "Support the shit out of them": Intersex emerging adults' recommendations for caregivers of an intersex child. *Sexuality & Culture*, *28*(4), 2143–2174. https://doi.org/10.1007/s12119-024-10223-1

- interACT Advocates for Intersex Youth. (2024, July). *Brochure for parents of intersex children*. <u>https://interactadvocates.org/wp-content/uploads/2024/07/BROCHURE-interACT-Parents-final-web-1.pdf</u>
- interACT Advocates for Intersex Youth. (2024, July). *Brochure for friends of intersex people*. <u>https://interactadvocates.org/wp-content/uploads/2024/07/BROCHURE-interACT-Friends-final-web-2.pdf</u>
- OII Europe. (n.d.). Supporting your intersex child: A parent's toolkit. https://www.oiieurope.org/supporting-your-intersex-child-a-parents-toolkit/
- Focus Features. (n.d.). *Every Body* [Film]. <u>https://www.focusfeatures.com/every-body</u>

Resources for human service professionals

- interACT Advocates for Intersex Youth. (2024, February). Intersex 101 handout: Doublesided posters [PDF]. <u>https://interactadvocates.org/wp-content/uploads/2024/02/Intersex-101-Handout-Double-Sided-Posters-2.pdf</u>
- interACT Advocates for Intersex Youth. (2022, October). Intersex variations glossary [PDF]. <u>https://interactadvocates.org/wp-content/uploads/2022/10/Intersex-Variations-Glossary.pdf</u>
- interACT Advocates for Intersex Youth. (n.d.). *Intersex brochures*. <u>https://interactadvocates.org/intersex-brochures/</u>
- interACT Advocates for Intersex Youth. (2023, October). *What we wish our therapists knew* [PDF]. <u>https://interactadvocates.org/wp-content/uploads/2023/10/What-We-Wish-Our-Therapists-Knew.pdf</u>
- interACT Advocates for Intersex Youth. (2024, July). *Brochure for doctors* [PDF]. <u>https://interactadvocates.org/wp-content/uploads/2024/07/BROCHURE-interACT-Doctors-final-web-2.pdf</u>
- interACT Advocates for Intersex Youth. (2024, July). Brochure for teachers [PDF]. <u>https://interactadvocates.org/wp-content/uploads/2024/07/BROCHURE-interACT-Teachers-final-1.pdf</u>
- interACT Advocates for Intersex Youth. (n.d.). *Intersex awareness day*. <u>https://interactadvocates.org/intersex-awareness-day/</u>
- The Trevor Project. (2021, December). *Intersex youth mental health report* [PDF]. <u>https://www.thetrevorproject.org/wp-content/uploads/2021/12/Intersex-Youth-Mental-Health-Report.pdf</u>

Professional literature

- Astle, S., et al. (2024). "Support the shit out of them": Intersex emerging adults' recommendations for caregivers of an intersex child. *Sexuality & Culture, 28*(4), 2143–2174. <u>https://doi.org/10.1007/s12119-024-10223-1</u>
- Israel, T., Ansara, Y. G., & Riggs, D. W. (2024). Intersex people's experiences of medical interventions, sex education, and physical intimacy. *Psychology & Sexuality*, 15(3), 278. <u>https://doi.org/10.1080/19419899.2023.2252446</u>
- Marinus, M. A., & Cense, M. A. (2024). A life course perspective on the sexual development of young intersex people. *Healthcare*, 12(1), 239. <u>https://pubmed.ncbi.nlm.nih.gov/38255126/</u>

- Sex education special issue: Intersex and sexuality education. (2021). Sex Education, 21(5). <u>https://www.tandfonline.com/toc/csed20/21/5</u>
- Simons, J. D., Gonzalez, J.-M., & Ramdas, M. (2020). Supporting intersex people: Effective academic and career counseling. *Journal of LGBTQ Issues in Counseling*, 14(2), 91–110. <u>https://doi.org/10.1080/15538605.2020.1790465</u>
- Jones, T. (2016). The needs of students with intersex variations. *Sex Education*, 16(6), 602–617. <u>https://doi.org/10.1080/14681811.2016.1149808</u>
- National Academies. (2022). *Measuring sex, gender identity, and sexual orientation, Chapter 7: Measuring intersex/DSD populations.* <u>https://nap.nationalacademies.org/read/26424/chapter/11</u>

Resources on supportive mental health care for intersex children and youth

- van de Grift, T. C., et al. (2024). Minority stress and resilience experiences in adolescents and young adults with intersex variations/differences of sex development. *Psychology of Sexual Orientation and Gender Diversity, Advance online publication*. <u>https://psycnet.apa.org/fulltext/2024-51548-001.html</u>
- Skaggs, C., & Wall, S. S. (2023). Intersex youth: A call for dignity in mental health care. In D. Lester & J. O'Reilly (Eds.), *The Palgrave Encyclopedia of Critical Perspectives on Mental Health* (pp. 1-6). Springer. https://link.springer.com/referenceworkentry/10.1007/978-3-030-12852-4 95-1
- Sanders, C., et al. (2021). What mental health supports do people with intersex variations want, and when? Person-centred trauma-informed life-cycle care. *Psychology of Sexualities Review*, 12(1), 5-19. <u>https://researchers.mq.edu.au/en/publications/what-mental-health-supports-do-people-with-intersex-variations-wa</u>

For additional resources and information, please see *Advancing Health Equity for Intersex Individuals,* Office of the Assistant Secretary of Health (OASH), U.S. Department of Health and Human Services (2025), available at <u>https://www.hhs.gov/sites/default/files/intersex-health-equity-report.pdf</u>.

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