DCU
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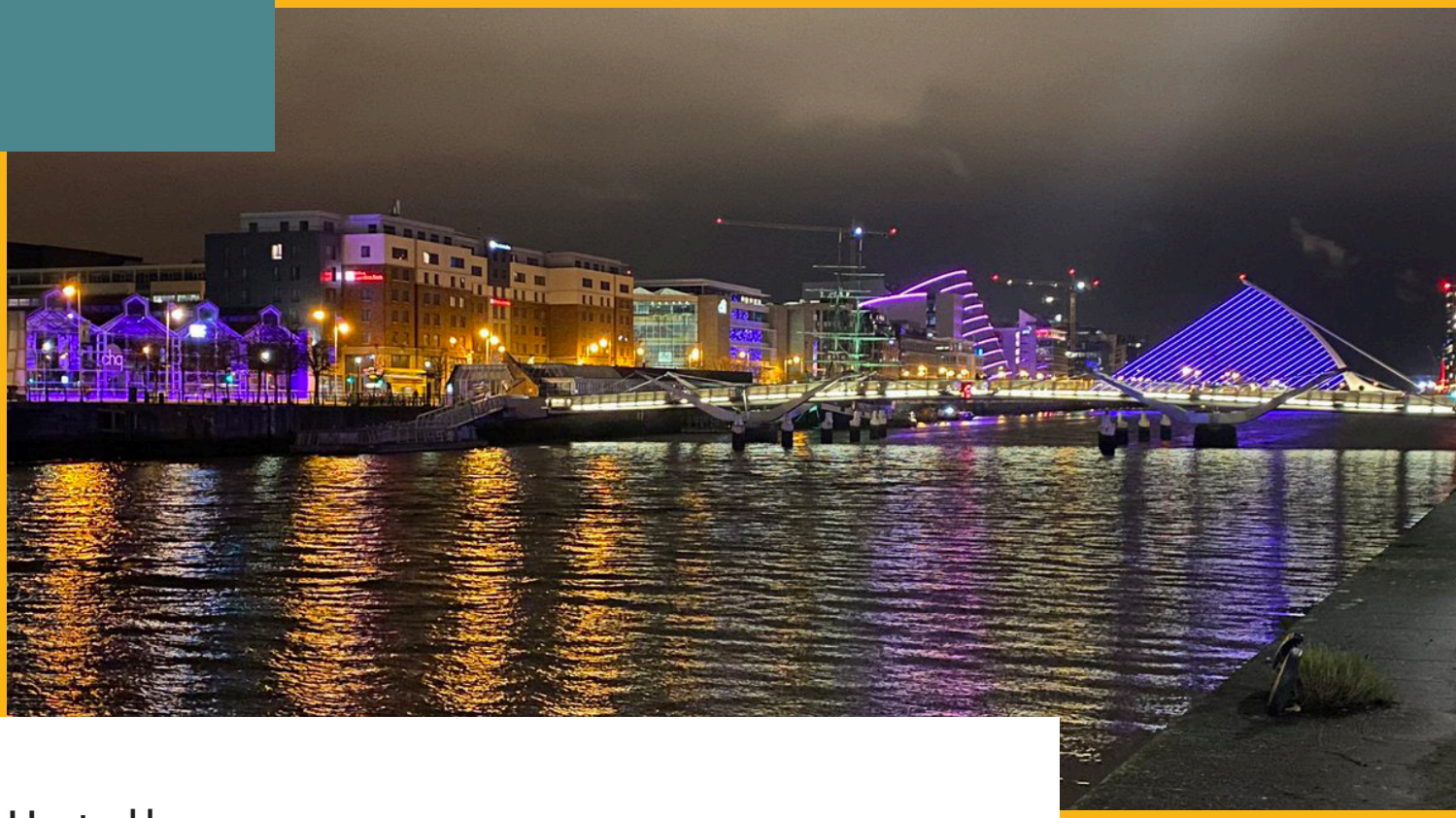
Dublin City University

Intersex 2021 - A Vision For the Future

Online Conference: 21st - 22nd April 2021



Hosted by

Intersex Mapping Study at DCU
DCU School of Law and Government
DCU School of Nursing, Psychotherapy and Community Health

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Intersex 2021 - A Vision For The Future

Conference Booklet

Table of Contents

Acknowledgements 2

Intersex 2021 - A Vision For The Future 3

CONFERENCE PROGRAMME 4

Day 1: Wednesday, April 21st 2021 4

Day 2: Thursday, April 22nd 2021 8

The Intersex Mapping Study at Dublin City University 10

Conference Code of Conduct 11

Language 11

International Representation at Intersex 2021 12

The Intersex Flag 13

ABSTRACTS 14

DAY 1 | Wednesday, 21st April 2021 14

DAY 2 | Thursday, 22nd April 2021 37

PROFILES - Our Conference Delegates 44

Acknowledgements

We wish to acknowledge the following people and organisations for their support of Intersex 2021 - A Vision For The Future.

DCU President Daire Keogh, colleagues in the President's Office, and all our colleagues at the School of Law and Government and the School of Nursing, Psychotherapy and Community Health. We also wish to thank our DCU Marketing and Communications colleagues and those at the Centre of Excellence for Diversity and Inclusion. And in another show of support, DCU lights will turn purple and yellow for the duration of the conference to mark *Intersex 2021*.

Special thanks to our EU Commissioner for Equality, Helena Dalli, for her support of our conference, her opening address and her office's committment to intersex equality across the European Union.

We wish to thank all those who accepted our invitation to act as chairs and who represent numerous state and non-profit organisations across Ireland.

We are grateful to Mr. Robert Wade, Photographer, for kindly granting permission for his image of the Rock of Cashel to feature on the back cover of this conference booklet. The front cover image, 'Liffey View, Dublin' was taken by Tanya Ní Mhuirthile as part of our *#IrelandTurnsPurple* campaign to raise awareness about intersex on Intersex Solidarity Day, 8th November 2020. Seventy buildings across Ireland supported our efforts and turned purple.

Finally, sincerest thanks are owed to Mr. Garvan Doherty our conference partner and producer.

go-to GARVAN

Intersex 2021 is kindly sponsored by Comfort Keepers Ireland - part of the Sodexo group.
The Irish Research Council continues to fund and support our research.

Intersex 2021 - A Vision For The Future

21st and 22nd April 2021

Online Conference hosted by

The Intersex Mapping Study at Dublin City University

School of Law and Government &
School of Nursing, Psychotherapy and Community Health

This interdisciplinary conference brings together a multiplicity of discourses about intersex/variations of sex characteristics (VSC) in society from around the world. This conference continues on an important path that takes intersex/VSC out of the historical confines in the medical space where babies, children, adults and their bodies have been problematised in the quest to "normalise" difference. Contemporary understandings of intersex/variations of sex characteristics demand more informed and multidisciplinary perspectives. This conference aims to provide an inclusive and diverse platform through which to listen and discuss intersex/VSC for the new decade.

CONFERENCE PROGRAMME

Please note all times are BST (London time)

Day 1: Wednesday, April 21st 2021

9am - Gathering **09:15 – 09:30 Opening Session – Main Room**	
09:15	**Conference Announcement |** Tanya Ní Mhuirthile, DCU
09:20	**Welcome Address |** Daire Keogh, President DCU
09:25	**Opening Address |** Helena Dalli, EU Commissioner for Equality
09:30 – 10:40 Plenary Session 1 – Main Room	
Chair: Tanya Ní Mhuirthile, DCU **Keynote Address 1** Morgan Carpenter Co-Executive Director Intersex Human Rights Australia, PhD Candidate in Bioethics, University of Sydney. **Keynote Address 2** Kitty Anderson Co-Chair OII Europe, Cofounder Intersex Iceland and Chairman of the Board of the Icelandic Human Rights Centre.	
10:40 – 11:10 Coffee Break	

11:10 – 12:30 Parallel Panels 1		
Breakout Room 1	**Breakout Room 2**	**Breakout Room 3**
Medicalisation of Intersex Chair: Philip Crowley, Health Services Executive Management of 'Disorders of Sex Development'/Intersex Variations in Children: Results from a Freedom of Information Exercise *Mitchell Travis, University of Leeds & Fae Garland. University of Manchester* Building the Variation. Exploring social beliefs and cultural factors influencing construction and medicalisation of intersex bodies *Marta Prandelli | University of Padova, Italy* "Uncertain knowledge. The production of ignorance in the medicalization of intersex people in France" *Michal Raz, L'ecole des Hautes Etudes en Sciences Sociales (EHESS). Centre de recherche medécine, santé, santé mentale, société (CERMES 3). Paris, France*	**Intersex & Activism** Chair: Gráinne Healy, Social Intelligence Associates Does intersex equal activist? Tensions between movement and community approaches of intersex identities and lives *Loé Petit, PhD candidate in Université Paris VIII* Intersex Activism in Italy *Manuela Falzone & Claudia Balsamo* Intersex advocacy in Aotearoa, New Zealand *Rogena Sterling, University of Waikato & Intersex Trust Aotearoa New Zealan*	**Global Perspectives** Chair: Lesley Dibley, University of Greenwich Intersex Lived Experience - Trauma and Growth in Australia and Aotearoa/New Zealand *Bonnie Hart, Intersex Peer Support Australia* Intersex Community in India and the Rights of Persons with Disability Act *Prashant Singh, Human Rights Lawyer & Coordinator Intersex Asia* Impact of Covid19 in the global south, experiences from a Colombian intersex health professional assisting intersex people at risk in South America. *Eliana Rubashkyn, Intersex Trust Aotearoa, Rainbow Path New Zealand, Brújula Intersexual*
12:30 – 13:30 Lunch		

13:30 – 14:45 Parallel Panels 2		
Breakout Room 1	**Breakout Room 2**	**Breakout Room 3**
Brújula Intersexual: a multidisciplinary perspective and multitasking project Chair: Amets Suess Schwend, Andalusian School of Public Health University of Granada The Origins of Brújula Intersexual *Laura Inter* *Founder and CEO at Brújula Intersexual* Thinking la intersexualidad, South of Río Grande *Hana Aoi* *Institution and Research CoOrdination at Brújula Intersexual* Intersex Call *Eva Alcántara Zavala Universidad Autónoma Metropolitana Xochimilco,* *Mexico |Intersex ally* Medical Needs for People Born With Intersex Variations *Carlos Alberto Narváez Pichardo M.D., Hospital San Ángel Inn, Coyoacán, Mexico city | Intersex ally*	**Conceptualising Intersex 1** Chair: Mary Donnelly, University College Cork From Addition to Recognition: A Historical Perspective on the I in LGBTQI *David Andrew Griffiths, University of Surrey* Introducing Mad Intersex Studies *Celeste E. Orr & Meg Peters* Intersex people and educating for the development of personality *Rogena Sterling, University of Waikato & Intersex Trust Aotearoa New Zealand*	**Lived Experience of Intersex** Chair: Ailbhe Smyth, Age Action Ireland Attitudes to intersex issues by secondary school students in Ireland and how to improve awareness *Bella FitzPatrick & Clara Barry, ShoutOut* XOXY: One Intersex Woman's Journey *Kimberly Zieselman, interACT: Advocates for Intersex Youth* The Well of Silence: Reflections on the Well *Chris North | Author, Advocate and Intersex Ally*
14:45 – 15:00 Coffee Break		
15:00 – 15:45 Plenary Session 2 – Main Room		
Chair: Mel Duffy, DCU **Keynote Address 3 |** Sara Philips, Chair Intersex Ireland		
15:45 – 16:15 Coffee Break		

16:15 – 17:30 Parallel Panels 3		
Breakout Room 1	**Breakout Room 2**	**Breakout Room 3**
Intersex Rights Chair: David Keane, Dublin City University U.S. Legislative Policy Campaigns to Protect Intersex Youth Alesdair Ittleson, *interACT: Advocates for Intersex Youth* *Mauro Cabral Grinspan, GATE* Walking the line: reforming intersex law in Argentina Reflexivity in intersex studies: Developing principles for human-rights based research practices and ethics *Amets Suess Schwend, Andalusian School of Public Health University of Granada*	**Conceptualising Intersex 2** Chair: Sindy Joyce Sociologist & Member of President Higgins' Council of State Intersex-people within theological frameworks, especially the roman-catholic tradition *Katharina Mairinger, University of Vienna* Intersex rights: Living between sexes *Nikoletta Pikramenou, Intersex Greece* Growing up 'round here: Considering Questions of Agency in Rural Intersex Narratives *Katelyn Dykstra, University of Manitoba In absentia*	**Medical Management of Intersex** Chair: Brenda Daly, Dublin City University Medical Doctors as Torturers? Dutch Responses to the UN Committee Against Torture's 2017 Recommendations Regarding Intersex Children in The Netherlands *Gijs Hablous, Radboud University Nijmegen* "Usually the mother:" Dilation and the medical management of intersex children *Celeste E. Orr, St. Lawrence University & Amanda D. Watson, Simon Fraser University* Agency-based model of intersex health as part of a larger conversation on intersex rights requests in medical settings *Daniela Crocetti, Academic Intersex Ally.* *Valentino Vecchietti, Independent Academic & Intersex Human Rights Activist, UK* *Surya Monro, University of Huddersfield;* *Tray Yeadon-Lee, University of Huddersfield*

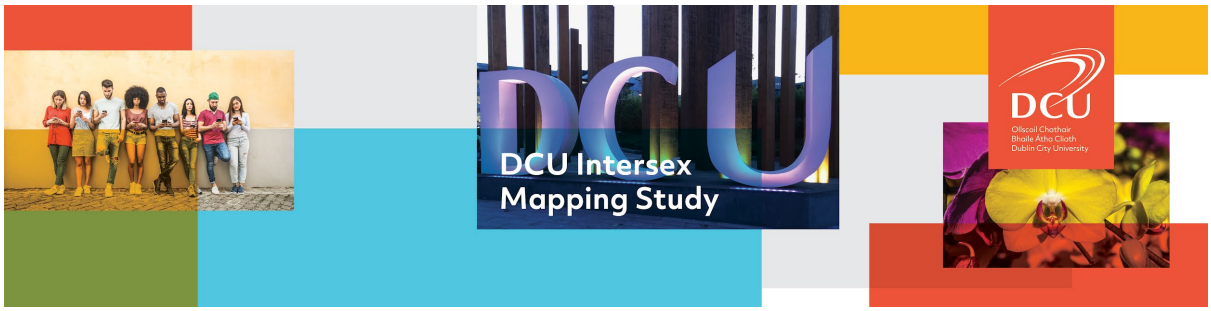
SOCIAL EVENT: Wednesday, 21st April 7pm

Day 2: Thursday, April 22nd 2021

09:30 – 09:35 Welcome to Day 2 – Main Room		
09:35 – 10:50 Parallel Panels 4		
Breakout Room 1	**Breakout Room 2**	**Breakout Room 3**
Intersex in the Arts Chair: Sophie Doherty, Dublin City University Film vs TV: Intersex representation in Australian media *Kamran Qureshi, University of East Anglia* Intersex: Crossing The Vocal Boundaries *Alexandros Constantis | Musicologist and Specialist Singing Voice Researcher/Consultant* *Stands a lady on the mountain.* The inculturation of gender roles through children's rhymes and games in early 20th Century Ireland *Carol Barron, Dublin City University*	**Introducing the Intersex: New Interdisciplinary Approaches (INIA) programme** Chair: Mauro Cabral Grinspan, GATE Surya Monro, *University of Huddersfield* Amets Suess Schwend, *Andalusian School of Public Health University of Granada* Yessica Mester, *Andalusian School of Public Health University of Granada* Daria Abrosimova, *University of Zurich* Adeline Berry, *University of Huddersfield* Axel Keating, *Dublin City University* Steph Lum, Dublin City University	**Family Experiences of Intersex** Chair: Michael Farrell, European Commission against Racism and Intolerance What meaning do parents give to variations in their child's sex characteristics? *Gaëlle Larrieu, PhD candidate (Sociology) at the Observatoire Sociologique du Changement (Sciences Po), France* Where was our consent? The healthcare experiences and family dynamics across intersex peoples' life stages. *Mandy Henningham, University of Sydney & Tiffany Jones, La Trobe University*
10:50 – 11:15 Coffee Break		
11:15 – 12:15 Plenary Session 3 – Main Room		

Chair: Morgan Carpenter, Co-Executive Director Intersex Human Rights Australia, PhD Candidate in Bioethics, University of Sydney **Panel Discussion |** Intersex Ireland
12:15 – 13:15 Lunch
13:15 – 14:15 Plenary Session 4 – Main Room
Chair: Irene Kuzemko, OII Europe **Mapping the Lived Experience of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy** Tanya Ní Mhuirthile | Mel Duffy | Maria Feeney The Intersex Mapping Study at Dublin City University
Closing Conference Remarks **14.15 - 14.20**

The Intersex Mapping Study at Dublin City University



We are the Intersex Mapping Study Team at Dublin City University. Our Principal Investigator, Dr Tanya Ní Mhuirthile from the School of Law and Government leads the study with colleagues, Prof Anthony Staines and Dr Mel Duffy, from the School of Nursing, Psychotherapy and Community Health and with Dr Maria Feeney, also from the School of Law and Government. We are delighted to welcome you all to our online conference *Intersex 2021 - A Vision For The Future*.

Tanya Ní Mhuirthile

Anthony Staines

Mel Duffy

Maria Feeney

Conference Code of Conduct

For all attendees:

1. Be inclusive – support people of all backgrounds, abilities, neuro-divergences, sexualities and identities;
2. Be respectful to all attendees and speakers. Verbal or physical aggression/disrespect will not be tolerated;
3. If you are a member of the media/press, please identify yourself to the conference organisers in a brief email to intersex@dcu.ie Thank you.
4. Avoid using stigmatising language;
5. Be respectful of individuals' self-defined gender identities and pronouns;
6. All events will be chaired. Speakers will be given time to receive questions after all papers conclude, please wait for the chair to invite questions. Indicate your wish to ask a question/comment by using the 'Raise Your Hand' option on Zoom (accessed via the 'Participants' or 'Reactions' facility in the toolbar.

For speakers:

1. Please respect the Chair of the panel when they facilitate the Q&A sessions after the presentations
2. Please be respectful, stay on topic and do not address interpersonal, academic,inter-activist, or any other disputes during your engagement with delegate

Language

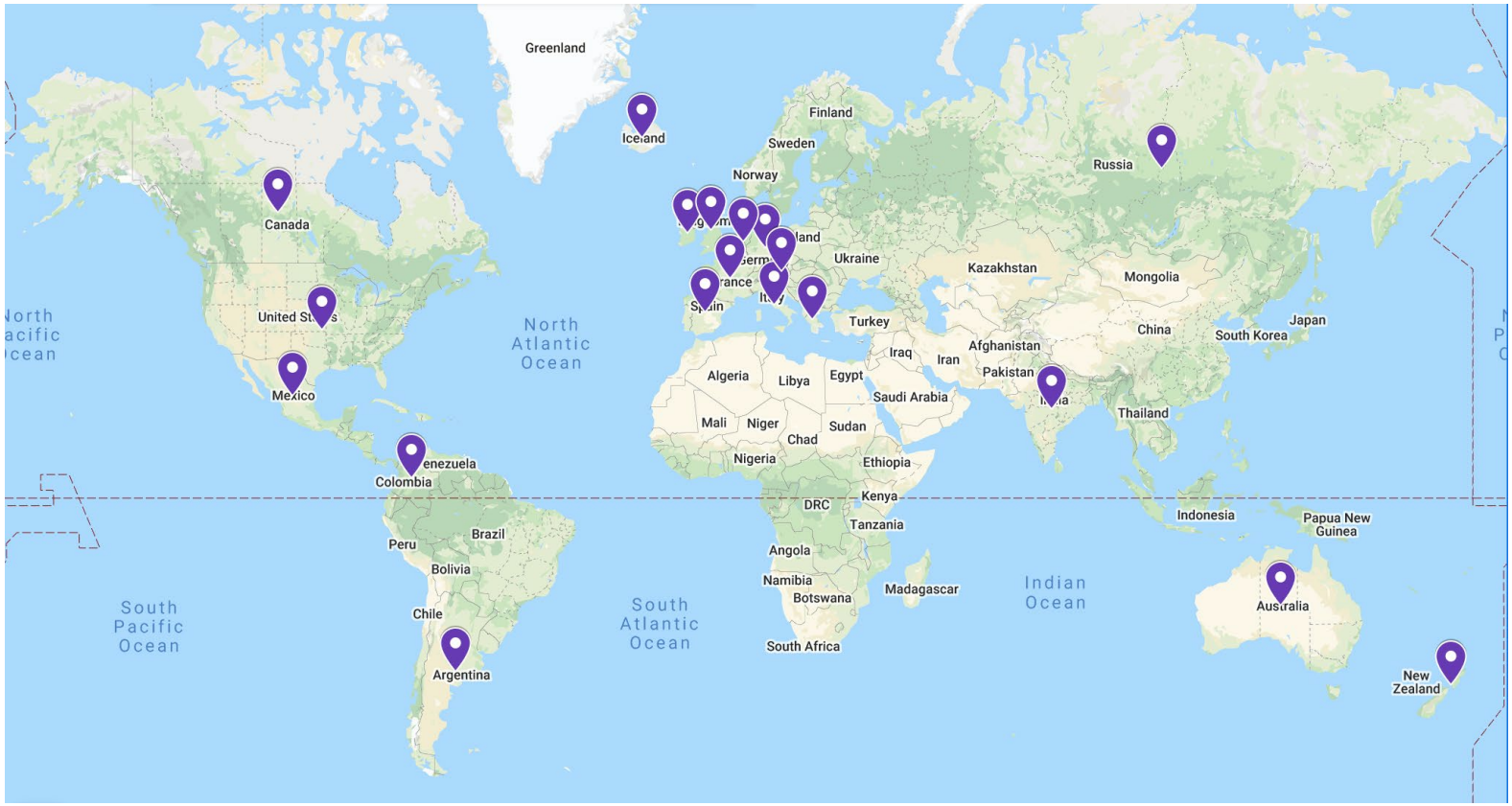
Using the proper language when we talk about people, their bodies and their experiences is very important to us and we are committed to speaking and writing about intersex as respectfully, and correctly, as possible.

In our Intersex Mapping Study we have used the terms 'Intersex' and Variations of Sex Characteristics (VSC).

We respect every individual's choice in terms of the words they use to talk about themselves. We encourage this acceptance from all throughout Intersex 2021.

International Representation at Intersex 2021

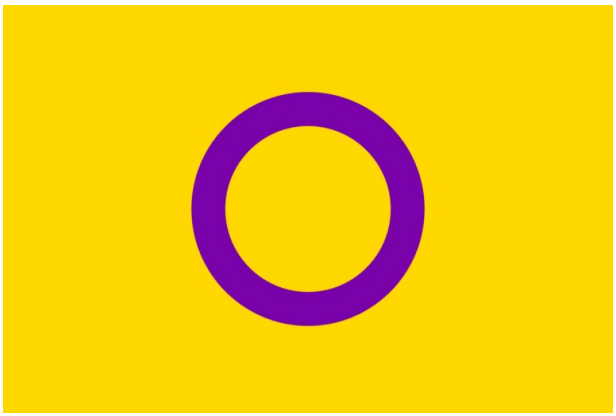
Delegates are presenting papers from 19 countries across the globe. Ireland, UK, France, Germany, The Netherlands, Spain, Italy, Greece, Austria, Iceland, Russia, Canada, United States, Mexico, Argentina, Colombia, India, Australia, New Zealand.



Source: https://www.google.ie/maps/@0.8256935,-51.8529807,3z/data=!3m1!4b1!4m2!6m1!1s1QxxA2OoNa4WA70pbgiuRpacErdRNVKmr?hl=en-GB&authuser=1

The Intersex Flag

The Intersex Flag was designed by Morgan Carpenter in 2013.
It features throughout our conference video streams. Read Morgan's story about its design.



"In 2013, I created a flag that has now travelled the world and is widespread within the intersex population. At the time, I was concerned with inappropriate symbols and iconography used to describe intersex people, often accompanying stories about us – images that have no firm grounding or basis in the history of the intersex movement, or the history of how intersex people have been (and are) treated. I still share those concerns, so I'm glad that the flag offers a constructive and meaningful alternative way to represent intersex people.
The flag is comprised of a golden yellow field, with a purple circle emblem. The colours and circle don't just avoid referencing gender stereotypes, like the colours pink and blue, they seek to completely avoid use of symbols that have anything to do with gender at all. Instead the circle is unbroken and unornamented, symbolising wholeness and completeness, and our potentialities. We are still fighting for bodily autonomy and genital integrity, and this symbolises the right to be who and how we want to be.

Intersex people are born with variations of physical sex characteristics that don't fit medical or social norms for female or male bodies. Intersex variations can be determined prenatally, at birth, at puberty, and at other times, such as when attempting to conceive a child.

Intersex people may have any sex assignment, sexual orientation or gender identity. People born with intersex variations face human rights violations before we have agency to freely express an identity. Sex assignment (if evident at birth) and unnecessary deferrable medical interventions are grounded in gender stereotypes and ideas about physical normality. Medical interventions are also intended to construct or reinforce heterosexual, cisgender identities."
Source: https://morgancarpenter.com/intersex-flag/

ABSTRACTS

DAY 1 | Wednesday, 21st April 2021

09:35 – 10:40 Plenary Session 1 - Keynote Addresses

Chair: Tanya Ní Mhuirthile, DCU

Keynote Address 1 | *Morgan Carpenter*
Co-Executive Director Intersex Human Rights Australia, PhD Candidate in Bioethics, University of Sydney.

Keynote Address 2 | *Kitty Anderson*
Co-Chair OII Europe, Cofounder Intersex Iceland and Chairman of the Board of the Icelandic Human Rights Centre.

Day 1: 11:10 – 12:30 Parallel Panels 1

Session 1: Medicalisation of Intersex

Chaired by: Philip Crowley, Health Services Executives

Management of 'Disorders of Sex Development' /Intersex Variations in Children: Results from a Freedom of Information Exercise *Mitchell Travis | University of Leeds, UK* *Fae Garland | University of Manchester, UK*
Building the Variation. Exploring social beliefs and cultural factors influencing construction and medicalisation of intersex bodies *Marta Prandelli | University of Padova, Italy*
Uncertain knowledge. The production of ignorance in the medicalization of intersex people in France *Michal Raz | École des Hautes Études en Sciences Sociales (EHSS) - Centre de recherche médecine, sciences, santé, santé mentale, société - CERMES 3*. Paris, France

Management of 'Disorders of Sex Development'/Intersex Variations in Children: Results from a Freedom of Information Exercise

Mitchell Travis | *University of Leeds, UK*

Fae Garland | *University of Manchester, UK*

Non-therapeutic medical interventions on the bodies of children born with Disorders of Sex Development (DSD)/intersex variations have been subject to increasing critical scrutiny. In response to recent criticism directed at the UK, and early moves to consider reform, we report on a Freedom of Information exercise that sought to evaluate whether NHS England is meeting international standards on optimal clinical management of DSD/intersex variations. The study explored what medical protocols are being followed to help inform potential reform, particularly with regard to non-therapeutic surgery. While the exercise revealed limited examples of promising practice, current protocols in the majority of Trusts appear unlikely to meet the complex needs of these children. We identify areas where significant improvement is needed, including: data management; consistency in guideline use; composition of multidisciplinary teams, and addressing disciplinary hierarchies within teams. These concerns sharpen criticisms of the lack of recognition of children's rights in this context.

Building the Variation. Exploring social beliefs and cultural factors influencing construction and medicalisation of intersex bodies

Marta Prandelli | *University of Padova, Italy*

The umbrella term Variations of Sex characteristics (VSC), also known as Intersex, indicates physical characteristics that diverge from what is generally expected to be found in - and believed as indicative of - a typically male or female body. Historically, medicine has long been the prevalent discipline on the topic, relying on the marks of biological sex that varied over time (genital appearance, sex hormones, sex chromosomes) as bases for children's sex assignment. Currently, there is not a universal consensus on the "management" of VSC/Intersex, and the existing guidelines and recommendation vary depending on the chosen perspective. However, the need to confirm socio-cultural expectations and demands is still a guiding principle for primary and secondary sex characteristics "normalising" surgeries on infants and children (Liao, Wood & Creighton, 2015). The urgency in appointing a univocal biological sex label at birth is connected to the fundamental social, rather than clinical, mandate to allocate an individual into a collective categorisation that can easily be read through social interactions. Therefore, an investigation of cross- cultural social prescriptions and proscriptions that influence the way societies have "treated" and still "treats" VSC seems pivotal. The proposed contribution builds upon an ethnographic research with Italian parents of children with a VSC and aims to share the theoretical background of a new comparative

project on social beliefs and cultural factors influencing construction and medicalisation of intersex bodies. Using a comparative and interdisciplinary approach to investigate meanings and cultural constructions applied to VSC/Intersex, this new project aims to contribute to the recent social, medical, ethical and juridical debate on the topic. The ultimate goal of the project is to compare the Irish and Italian situations.

Uncertain knowledge. The production of ignorance in the medicalization of intersex people in France

Michal Raz | *Centre de recherche médecine, sciences, santé, santé mentale, société - CERMES 3*. Paris, France

The paper explores the mechanisms of ignorance production around intersexuality in relation to the biomedical sphere. Several scholars have shown that the body, particularly the female body, has been the scene of an "epistemology of ignorance" (Tuana 2004). In effect, ignorance, as noted Proctor (2008), refers to a complex political and sexual geography. Using this theoretical frame, as well as other related concepts such as "Undone science" (Frickel & al. 2010) and "uncomfortable knowledge" (Rayner, 2012), this paper focuses on the ways in which medicine, science and technology participate in a continuous process of erasing intersexuality. More specifically, this paper analyzes practices of secrecy, scientific bias and other forms of invisibilization of lived experience (Bastien-Charlebois 2014) and proposes to put into light a larger logic of obliteration. After listing the mechanisms of erasing bodies, variations and archives, the paper will concentrate on a specific case in which uncertain knowledge and ignorance are produced: Follow-up "quality of life" or "long term outcome" studies in France.The internal tension contained in the expression "uncertain knowledge" aims to underline that all scientific knowledges, technologies and medical practices on intersex belong to a specific "régime the vérité" (Foucault 2012) whose premises and consequences are left unquestioned. This regime persists in spite of multiple zones of uncertainty and controversies raised from the inside or outside of the medical profession. By unraveling mechanisms of ignorance production, the paper shows that a new paradox emerged: the increasing biomedical knowledge and techniques during the 20th Century mainly produced more and more questions, dilemmas and debate.

The persistence of the medical monopole over intersexuality in France can then be understood as a form of continual resistance, trying to maintain the pathologization of intersex variations.

These reflections grow from my PhD research, tracing an archeogenealogy of the medicalization of atypical sex in France since the 1950s. The materials used are both scientific literature analysis and interviews with medical practitioners who have been dealing with this issue.

Session 2: Intersex and Activism

Chaired by: Gráinne Healy, Social Intelligence Associates

Does intersex equal activist? Tensions between movement and community approaches of intersex identities and lives *Loé Petit | PhD candidate in Université Paris VIII, France*
Intersex Activism in Italy *Manuela Falzone | Intersex activist, member of IntersexEsiste and AISIA, Italy* *Claudia Balsamo | Intersex activist, Co-founder of IntersexEsiste, High school teacher, Italy*
Intersex advocacy in Aotearoa, New Zealand *Rogena Sterling| University of Waikato & Intersex Trust Aotearoa, New Zealand*

Does intersex equal activist? Tensions between movement and community approaches of intersex identities and lives

Loé Petit *| PhD candidate in Université Paris VIII, France*

One of the specificities of intersex, separating it from other gender-based oppressed identities, is that in Western countries where the systematic oppression of intersex persons has been developed around the notion of infant "correction" there was no preexisting community or collective identity. Thus, the way intersex has been built in the medical community as an umbrella term for variations that are considered as pathologies, has created by itself the population who will then be able to reclaim the term. As it is well-known, once the term has been reclaimed by the human rights based intersex movement, the medical profession decided to change it for "disorders of sex development". But the term "intersex" is still used as a rallying point for people with variations of sex development.

In that respect, another specificity of intersex is that the intersex movement, directly born from the medical creation of a repressed category, has been trying in many places throughout the world, to create a community, with intersex organizations are working hard to create a collective intersex identity with symbols and references. But because this project is coming from an activist perspective, and is activist-led, with spaces created by activists, it appears difficult for many groups to build and maintain a community with a diversity of sensitivities,

and to be inclusive and connected with people that for many reasons do not join activist networks.

This paper will examine the tensions between an approach of intersex identities and lives from the human rights activist point of view, and an approach of intersex identities and lives as non-political and/or defending the need for non-activist community spaces, and will present the strategic options developed to face these tensions.

Intersex Activism in Italy

Manuela Falzone *| Intersex activist, member of IntersexEsiste and AISIA, Italy*

Claudia Balsamo *| Intersex activist, Co-founder of IntersexEsiste, High school teacher, Italy*

Starting from the first Italian forum held in October 2020 amongst Italian intersex associations, activists and advocates, our purpose is to talk about the state of intersex activism in Italy. Among the national actions shared during the forum, a new entity founded by a group of parents with the explicit purpose of defending their children's integrity is worth noting. Additionally, the importance of the collaboration between the world of social sciences and the world of law in association with allied doctors was highlighted. On the political level, the absence of intersex issues emerged while discussing the new Zan law, a national anti-discrimination bill that makes misogyny and violence against LGBT and disabled people a hate crime. It was therefore decided to establish a working table for a bill that bans nonconsensual interventions. Consequently, a historic meeting was held in February 2021 between executives of the ISS - Superior Institute of Health - and activists, with the aim to start a public support project for intersex people. Finally, we want to underline the work of IntersexEsiste, carrying on training activities aimed at LGBTI+ associations and psychologists while expanding its field of action seeking political interlocutors who are able to support intersex rights both in Italy and among international organizations.

Intersex advocacy in Aotearoa New Zealand

Rogena Sterling*| University of Waikato & Intersex Trust Aotearoa, New Zealand*

The purpose of this presentation is to look at the history of intersex advocacy in Aotearoa New Zealand. Look at how it developed, the creation of Intersex Trust Aotearoa New Zealand (ITANZ). It will begin from the establishment of ITANZ and move through the journey of the Trust through to today. Furthermore, also look at the current projects and work that is currently underway or are being planned. In addition, the presentation will outline areas of focus of legislation and policy that ITANZ see as importance to work on to enable better lives of intersex people. After that it will consider the current intersex with fellow organisations in Australia, in particular through the Darlington Statement.

Session 3: Global Perspectives

Chaired by: Lesley Dibley, University of Greenwich

Intersex Lived Experience - Trauma and Growth in Australia and Aotearoa/New Zealand *Bonnie Hart | Intersex Peer Support Australia*
Intersex Community in India and the Rights of Persons with Disability Act *Prashant Singh | International Lawyer & Consultant, CoOrdinator Intersex Asia, Co-founder India Rights Initiative, India*
Impact of Covid19 in the global south, experiences from a Colombian intersex health professional assisting intersex people at risk in South America. *Eliana Rubashkyn | Intersex Trust Aotearoa, Rainbow Path New Zealand, Brújula Intersexual*

Intersex Lived Experience - Trauma and Growth in Australia and Aotearoa/New Zealand

Bonnie Hart *| Intersex Peer Support Australia*

Intersex people have diverse bodies and identities but are unified by experiences of pathologisation, enduring human rights violations, stigmatisation, and mental health issues stemming from shame and secrecy. This session presents psychological findings from an interpretative phenomenological analysis of personal narratives collected during reflective writing exercises at intersex peer support conference in Australia and Aotearoa/New Zealand. Themes unpacked include systematic pathologisation, negative embodiment, voice and truth, and the role of community. The narratives presented depict movement in perceived experience of how experiences of systematic pathologisation of intersex bodies were negatively impacted sense of self, family function, and social agency towards overcoming epistemic injustice, developing self-acceptance and increased social connection. These findings are contextualised in terms of posttraumatic growth and their implication for development of affirmative healthcare services for intersex people, the importance of psychosocial support as a primary intervention, and strategies for the effective integration of intersex peer support within multi-disciplinary teams.

The collection of narratives used in this study, *Our Collective Story,* was written by the co-authors with the intention for public publishing. As such a reading of the story could also be

presented as an adjacent session to give voice to the rich accounts of individuals' lived experiences they contain.

Intersex community in India and the Rights of Persons with Disability Act

Prashant Singh *| International Lawyer & Consultant, CoOrdinator Intersex Asia, Co-founder India Rights Initiative, India*

Members of the intersex community in India have largely been absent from the civil rights legal discourse and consequently, do not constitute a protected class. Consequently, such individuals often face varying levels of discrimination such as stereotyping, medicalizing, pathologizing, and societal misunderstandings. With the passage of the Rights of Persons with Disabilities Act (RPwD Act), the Parliament has significantly expanded the definition of disability in the statute. Under the amendments, more people qualify as individuals with disabilities protected by central disability law, prompting the question of how the disability law may be a source of protection for intersex individuals.

This paper explores the recently amended RPwD Act and addresses whether intersex individuals can be considered qualified individuals with a disability under the new definition. Examining the components of the statute as well as the recent amendments, this paper will also discuss whether disability law may be an optimal avenue for advancing the socio-political rights and public perceptions of the intersex community. This paper presents arguments supporting and opposing the application of the RPwD Act to protect intersex individuals in accessing public services, employment, health and education. It also examines the merits of applying the RPwD Act to intersex individuals through an examination of experience of other countries such the United States which have adopted a similar approach. Ultimately, this paper explores how the RPwD Act can serve as an added source of protection for an often hidden and forgotten community in immediate need of these protections. In 2019, India also passed a Transgender Persons Act which aims to protect intersex individuals as well. However, there are serious flaws in the law due to which it has the potential of setting the clock back on intersex human rights movement in India.

Intersex children in India are at constant risk of forced surgical and medical intervention in the form of sex reassignment surgeries. In this paper, the authors have made an attempt to highlight the need for a nation-wide ban on such surgeries. The paper also provides an insight into the current discourse around SOGIESC issues in India and future of law-making with respect to protection of human rights of intersex children through disability law in particular and human rights legislations in India.

Impact of Covid19 in the global south, experiences from a Colombian intersex health professional assisting intersex people at risk in South America.

Eliana Rubashkyn *| Intersex Trust Aotearoa, Rainbow Path New Zealand, Brújula Intersexual*

Eliana's personal testimony about their work is an important and timely contribution to Intersex 2021. In their capacity as a pharmacist, Eliana has been involved in the emergency response to the COVID-19 pandemic - specifically with the intersex community in their region. They are working on research to identify the needs and the emergencies that have erupted by disruption of health services and reprioritization of services.

Unfortunately, many intersex people have died as a result of neglect, lack of access to medications that are used for treating COVID-19 patients (such as Hydrocortisone and other life-saving medications in babies and children with CAH), and more. Even in Venezuela, an intersex activist is experiencing a life-threatening condition as a result of chronic starvation and lack of intersex medical care. "*We are currently providing all the assistance we have in our hands. And despite huge health burdens during the pandemic, intersex unnecessary surgeries are still happening and this is evident in some cases we have been working within Mexico, Colombia, Peru, Brazil, and Argentina* indicates Eliana.

Moreover, as a former refugee, Eliana is well-placed to discuss this intersection in our wider intersex community - an often forgotten and ignored issue in a world with more than 30 million refugees.

Day 1: 13:30 – 14:45 Parallel Panels 2

Session 1: International Case Study - Mexico. Panel Discussion

Chaired by: Amets Suess Schwend, Andalusian School of Public Health University of Granada

MEXICO *Brújula Intersexual: a multidisciplinary perspective and multitasking project*

Laura Inter *| Brújula Intersexual's Founder and CEO, Law Degree and intersex activist*

Hana Aoi *| Vivir y Ser Intersex´s founder and coordinator & research coordinator at* Brújula

Eva Alcántara Zavala *| Research Professor at Universidad Autónoma Metropolitana Xochimilco, Mexico and general advisor in Brújula Intersexual*

Carlos Alberto Narváez Pichardo *| M.D., Hospital San Ángel Inn, Coyoacán, Mexico city, intersex ally*

In this panel we are interested in addressing the work that we have carried out in the Brújula Intersexual project since 2013, whose mission is to denounce violations of the right to self- determination and body integrity and autonomy that affect people born with intersex bodies. Our main objective is to transform medical practices and social representations of intersex bodies and contribute to the critical reflection of sex and gender. In this way we influence the profound transformation of gender relations by challenging the naturalization of bodies and sex stereotypes.

Our team is multidisciplinary and that has allowed us to cover several areas of incidence: community building; advocacy work, spread of information, visibility, awareness and transformation of the problems that intersex people face by a human rights approach; research, through the production of articles and academic papers; advice to strategic groups, state and federal institutions, and decision makers; participation with various media; organizing workshops and talks to specific people or the general public; collaboration in the preparation of documents that affect the transformation of public policies; submitting reports on the situation of intersex people before various international human rights bodies; support in clinical care for people with variations in sex characteristics of different ages; among other.

- **Participation in national, regional and global activism, and the incidence to change medical practices and influence public policies from the human rights platform.**

In 2017, we achieved that the *Secretaría de Salud* (Ministry of Health) published the "Guide of recommendations for the Care of Intersex and Variation in Sex Differentiation", as part of the "Protocol for Access without Discrimination to the Provision of Health Care Services of LGBTTT and Intersex persons." This document is an advance in the recognition that medical practices in relation to variations in sex characteristics should be reviewed from a human rights perspective. Since 2016 we have collaborated with advisory services and specific projects with the *Consejo Nacional para Prevenir la Discriminación* (National Council to Prevent Discrimination), for the creation of public policies aimed at protecting intersex human rights, including the first Intersex Survey in Mexico. We have also participated in advising anti-discrimination organizations in other Latin American countries. Together with the Swiss NGO StopIGM.org and local intersex activists and people, we have submitted reports on intersex genital mutilation in Mexico and Spain to the CRC 2017, CEDAW 2018, and CCPR 2019. Thanks to these reports, Mexico and Spain were reprimanded for Intersex Genital Mutilation by the UN.

- **Community building, care strategies and empowerment of Spanish-speaking intersex people.**

From Mexico we have managed to build the first community of Spanish-speaking intersex people, it is a network that include several Spanish-speaking countries. For 6 years we have focused on making it grow and keeping it together. We maintain contact with more than 250 intersex people and families, we provide support according to their needs and our possibilities: peer group, information, emotional and psychological support. Thanks to these interactions we have collaborated directly in the conformation of various intersex organizations and projects in several Spanish-speaking countries such as: Argentina, Spain, Colombia and Chile.

- **Meeting and feedback between activism and academy.**

In Brújula Intersexual, academy and activism converge and feedback. In addition to Laura Inter who remains in constant training, the core of the project includes a research professor, a clinical doctor and two graduate students. Two people in that nucleus are intersex activists and the other three people recognize themselves and are recognized as intersex community allies. In Brújula Intersexual we consider that writing and reading are two fundamental tools of transformation. We have published several articles and academic papers in collaboration. The link between activism and academy has allowed us to recognize that research is essential; We make research a strategy that affects the social and cultural transformation required to change the care of intersex people from a human rights perspective.

Session 2: Conceptualising Intersex 1

Chaired by Mary Donnelly, University College Cork, Ireland

From Addition to Recognition: A Historical Perspective on the I in LGBTQI *David Andrew Griffiths | University of Surrey, UK*
Introducing Mad Intersex Studies *Celeste Orr | St. Lawrence University, New York, USA* *Meg Peters | University of Ottawa, Canada*
Intersex people and educating for the development of personality *Rogena Sterling| University of Waikato & Intersex Trust Aotearoa, New Zealand*

From Addition to Recognition: A Historical Perspective on the I in LGBTQI

David Andrew Griffiths | University of Surrey, UK

The question of whether to "add" the I to the LGBT+ acronym is a significant one. Some see experiences and understandings of prejudice as reason for inclusion along with resource-sharing. Others, however, have questioned whether LGBT+ communities and organisations have fundamentally different priorities which can distract from or even erase the specific demands of intersex/vsc communities. In this paper I will provide a historical perspective, looking at key moments in British LGBTQI history in the late 1960s and early 1970s. Intersex has historically done a lot of conceptual work in the biomedical and legal understandings of non-normative gender and sexuality. Conversely, intersex experiences and needs have often been understood through a lens of gender and sexuality. While this relationship has not been unproblematic, it is one that needs attention. I will argue that we need to shift the focus from "addition" to "recognition". I will stress that intersex has a long history alongside (and often at the centre of) LGBT+ histories and that this deserves recognition. Not only this, but this "recognition" should be the starting point of what political philosophers have called a "politics of recognition". This shifts the question from whether to "add" the I to the LGBT+ acronym to the question of what responsibilities come with a politics of recognition, and the important question of how to build broad LGBTQI communities and solidarities while not erasing the specific needs and demands of intersex communities.

Introducing Mad Intersex Studies

Celeste Orr | *St. Lawrence University, New York, USA*

Meg Peters | *University of Ottawa, Canada*

While the intersection of intersex and disability – interphobia and ableism – has been established (Orr 2018), scholars have yet to examine intersex medical management through a Mad Studies lens. Doctors are represented as "half-crazed" by some intersex people (Karkazis 2008: 2). Some intersex individuals describe the male-female sex binary and the medical system as "insane" (Amy and Lyra qtd. by Costello 2016: 87, 96), while at the same time being physically traumatized and diagnosed with "crazy" conditions by doctors. Mad Studies encourages a deeper investigation into both traumatizing "crazy" systems and the real cognitive differences that Mad people identify in themselves, making it an ideal field to connect to Intersex Studies.

Our paper proposes a number of potential intersections between Intersex and Mad Studies. First, we argue, in the attempt to maintain the sex binary and jurisdiction over intersex people's "body-minds" (Clare 2017), medical professionals presume intersex individuals are "crazy" when they reject or challenge "curative violence" (Kim 2017: 10). For example, Aldo reports, doctors "act as if I'm crazy" for not wanting medical intervention (Aldo qtd. by Costello 2016: 95). This can be contrasted with the "madness" of trans people who must prove their gender dysphoria in order to receive medical intervention (Smith 2018; Davis,

Dewey, and Murphy 2016). Mental health has a direct relationship, therefore, with gender/sex characteristics where endosex and cisgender sanity is maintained as normal. Cissexism and interphobia intersect with sanism through the medical management of intersex and trans body-minds.

Second, we turn to the work of Dian Million (2013), who argues that Indigenous peoples are often forced into systems that have already traumatized them in order to receive therapeutic care. In addition to the fact that the male-female sex binary is a sacrosanct Western concept that has been integral to colonizing projects (Magubane 2014; Mitra 2014; Cannon 1998), we argue that intersex people also experience re-traumatization through the medicalization of mental health care. In the attempt to impose and justify curative violence, medical practitioners may send "difficult" intersex patients "to psychologists for psychiatric 'treatment'" (Wilson 2012: n.p.); refusing to endure the pain of curative violence "is seen as a kind of madness, a type of insanity" (Wilson 2012: n.p.). In turn, intersex individuals are forced to continue receiving medical "care" within a new mental health framework.

Third, we argue that anti-Black sanism (Meeria, Abdillahi, and Poole 2016) manifests through medical intervention on intersex people's bodies, even if these bodies are white. For centuries, Black people's genitals have been represented as diseased, "malconformed," and ambiguous (Magubane 2014: 769); medical professionals maintained intersex "abnormalities" were more frequent in "Negros and related races" (Charlewood 1956: 12; also see Ramsay et al. 1988: 9). Given that interphobia relies on racialized understandings of proper genitalia, the unruly Black body-mind is a ghost within intersex medical management.

Finally, we propose an embodied understanding of madness that goes beyond mind/body separation. We look specifically to personal narratives that show how medical intervention in the body can bring "crazy" with it:

> After these operations, my family moved. The next physician used a dilating procedure where a thin catheter was inserted, curling up inside the bladder, followed by a thicker catheter. Each increase in thickness required the lead catheter to curl up inside the bladder. It drove me crazy, but then we move again, and the procedure used by the physician in the new neighborhood was worse. He used steel probes to force the stricture. (Nicholson 1999: 201)

We propose an investment in body-mind explorations, linking together Mad Studies and Intersex Studies while also challenging the inherent racism, interphobia, cissexism, sanism, and ableism of medical systems.

Intersex people and educating for the development of personality

Rogena Sterling | *University of Waikato & Intersex Trust Aotearoa, New Zealand*

While much has been written about the right of access to education, less attention has been given to the right to education in a form 'directed towards the full development of the human

personality.' To understand what this might mean, it is important to locate discussion within the broader frame of human rights. For too long, intersex people have been denied the right to education that provides for free and full development of personality within the education environment. The article uses a review of international human rights legislation and data from the few available studies to illustrate the issues intersex people face in schools and other education settings, and which must be addressed by future development and reform in schools and in the education system.

Session 3: Lived Experience of Intersex 2

Chaired by Ailbhe Smyth, Age Action Ireland

Attitudes to intersex issues by secondary school students in Ireland and how to improve awareness *Bella Fitzpatrick | ShoutOut, Ireland* *Clara Barry | Intersex Activist with ShoutOut and Intersex Ireland*
XOXY: One Intersex Woman's Journey *Kimberley Zieselman | interACT: Advocates for Intersex Youth, USA*
The Well of Silence: Reflections on the Well *Chris North | Author, Advocate and Intersex Ally*

Attitudes to intersex issues by secondary school students in Ireland and how to improve awareness

Bella Fitzpatrick *| ShoutOut, Ireland*

Clara Barry | *Intersex Activist with ShoutOut and Intersex Ireland*

ShoutOut is a registered charity operating on the Island of Ireland for the past 8 years. ShoutOut delivers educational workshops on LGBTQI+ issues primarily in secondary schools with students, but also with teachers, youth workers, social workers, and many other places which deliver services. The ShoutOut workshop which is delivered to secondary school students is 1 hour long and focuses on inclusion and destigmatising. ShoutOut has always included Intersex as part of the LGBTQI+ community and we always include Intersex people and issues in our workshops. We are lucky to have been guided by intersex people when developing our material. In the past 8 years, we have delivered over 1500 workshops to 45,000 students. In turn, this means we have spent collectively 1500 hours introducing and clarifying Intersex issues to teenagers across Ireland. Our proposal is to survey the facilitators of the workshops about their experiences discussing intersex issues with secondary school students, the common responses and misconceptions and how we could best tackle this going forward. We often face disagreement from the students as they may have been given inaccurate, or incomplete information from their science teacher regarding the existence of variation in sexual characteristics among humans. While when working with adults in capacity building training the questions on this topic are generally quantitative, e.g. what is the percentage of intersex people etc, students tend to ask more qualitative questions, e.g. "what does this mean for their sex life" etc. We find these questions are more best of the wellbeing of the individuals, particularly after we discuss IGM. We 149 active volunteers who have facilitated an average of 9 workshops each. We will send them all the survey and expect a return of over 40 complete surveys.

XOXY: One Intersex Woman's Journey

Kimberley Zieselman *| interACT: Advocates for Intersex Youth, USA*

Drawing from her personal and professional experience, and recently published Memoir, "XOXY" (Jessica Kingsley Publishers) conference attendees will meet "Kimberly, a suburban housewife and mother, whose discovery later in life that she was born intersex fueled her to become an international human rights defender and globally recognized activist."

Through a power point presentation combined with readings from her book, Kimberly will share her intersex discovery and her journey to self-acceptance and discuss how being intersex impacted her personal and family life, as well as her career. From uncovering a secret that was intentionally kept from her, to coming out to her family and friends and fighting for intersex rights, her candid and empowering story helps breakdown barriers and misconceptions of intersex people and brings to light the trauma and harmful impact medical intervention continues to have on the intersex community.

Kimberly will emphasize the importance of intersex narratives being shared through various mediums in order to educate general society and ultimately change hearts and minds that will help contribute to wider policy changes to support the intersex community. Following the presentation there will be time for open dialogue with Kimberly and amongst the attendees.

The Well of Silence: Reflections on the Well

Chris North | *Author, Advocate and Intersex Ally*

My proposal is to illustrate aspects of my life as an intersex person from the early 1950's to 2000's and to demonstrate the significance and benefits of a multi disciplinary, holistic approach to care. I was born in 1946 and life was experienced through the medicalisation of my body and the historic attitudes of the time to intersex. These caused profound consequences throughout my life. Secrecy was a major element of the treatment and became a constraint, a cause of lifelong deprivation. I felt I was damaged, needing correction. As a child and teenager, the treatments of my body were both emotionally and physically painful and a mystery to me. At twenty one however, I discovered my 'inner world', a contradiction to my fundamentalist Christian upbringing. Through 'self work' and self discovery, including Jung, I discovered I wasn't just 'body'. My life experiences paradoxically were enriching. I became very empathetic, intuitive, creative and began seeing life at many levels. I became a teacher, social worker for disabled children and creative arts practitioner. However, the early treatment policy of normalisation through surgery, testosterone therapy and impact of secrecy, extended into my adulthood and affected my interpersonal relationships and familial life. My adult medical experiences persisted in a way that I was and still am only seen as a physical body, not a multifaceted person with psychological, emotional, sexual and spiritual needs. I believe a multi-disciplinary, holistic approach to my life throughout childhood, adolescence and adulthood, including my decisions at the appropriate time about my gender, would have enabled a better adjustment to my world, development of my Self and a broader, richer and more fulfilled life.

Day 1: 15:00 – 15:45 Plenary Session 3

Chaired by

Keynote Address 3 | Chaired by: Mel Duffy, Dublin City University *Sara Philips | Chair Intersex Ireland*

Day 1: 16:15 – 17:40 Parallel Panels 3

Session 1: Intersex Rights

Chaired by: David Keane, Dublin City University

US Legislative Policy Campaigns to Protect Intersex Youth *Alesdair Ittleson* | Lawyer *interACT: Advocates for Intersex Youth, USA*
Walking the line: reforming intersex law in Argentina *Mauro Cabral Grinspan | GATE*
Reflexivity in Intersex Studies: Developing Principles For Human Rights-based research practices and ethics *Amets Suess Schwend | Andalusian School of Public Health - University of Granada, Spain*

U.S. Legislative Policy Campaigns to Protect Intersex Youth

Alesdair Ittleson *| Lawyer at interACT: Advocates for Intersex Youth*

Legislative recognition of intersex lives is at an all-time high across the world. interACT: Advocates for Intersex Youth is one of the largest intersex-led NGOs in operation and is behind the first ever successful legislative effort in the United States to name the harms faced by intersex people in medical settings. As activists continue to engage with lawmakers and others responsible for policy to protect this population, increasing awareness has led to an uptick in mention of the "i" , yet there is a lack of common understandings on behalf of those in power regarding best practices to achieve meaningful change for the intersex community. Questions remain including to what extent the impacted group can and should be involved in decision-making, how to allocate resources in an equitable manner, and the impact of trauma on activism and the long term sustainability of the movement. This presentation suggests guiding principles to ensure good outcomes, including examples of legislation and related media, as well as potential pitfalls to avoid.

Participants will engage with Kimberly Zieselman, the Executive Director of interACT: Advocates for Intersex Youth. Ms. Zieselman has over 20 years of experience in advocacy and is the author of the forthcoming memoir *XOXY*, charting her intersex discovery and journey to self-acceptance, fuelling her to become an international human rights defender and globally recognized activist.

Walking the line: reforming intersex law in Argentina

Mauro Cabral Grinspan | *GATE*

The Bill on the C*omprehensive Protection of Sexual Characteristics* introduced in the Parliament between 2018 and 2019 demands a radical reform of the legal situation of intersex people in Argentina. The proposed reform is based on human rights principles, including the right tto freedom from torture or cruel and inhuman treatment, and the right to the truth. If approved, the Bill will draw an unprecedented normative line between acceptable and unacceptable medical practices in the country. This paper will map some sections of that line, as well as the times and spaces surrounding it.

Reflexivity in intersex studies: Developing principles for human rights-based research practices and ethics

Amets Suess Schwend | *Andalusian School of Public Health - University of Granada, Spain*

The human rights perspective has achieved an increasing relevance for framing intersex rights. The Yogyakarta Principles and Yogyakarta Principles +10 contribute an application of the international human rights law in relation to sexual orientation, gender expression/identity and sex characteristics. International intersex activism demand the human rights protection of intersex people, denouncing non-consensual surgical interventions and other treatments, pathologising diagnostic classifications and frequent lack of access to medical records. Over the last years, international and regional human rights bodies, among them the UN, the European Parliament and the Council of Europe, call Member States to end non-consensual and medically unnecessary surgeries on intersex children. In some countries and regions, these surgeries are prohibited by law. In research, an emerging field of intersex studies can be observed. This paper aims at analysing the role of the human rights perspective in intersex studies, and the contribution of intersex studies to research epistemologies, methodologies and ethics.

Methods: Narrative literature review, including academic publications, legislation, strategic documents and activist declarations.

Results: Intersex studies develop a body of critical knowledge on clinical practices, diagnostic classifications and research practices, using frequently a human rights perspective in their analyses. Intersex authors and allies break with a tradition of research 'on' intersex people without their participation and question pathologising conceptualizations, diagnostic classifications, terminologies and visual representations in research. They develop reflections on the ethical responsibility of doing research from an academic-activist perspective and the relevance of reflexivity regarding their own position, trajectory and theoretical framework. Intersex authors and allies also develop proposals for non-pathologising and human rights-based terminologies. Finally, they propose principles for human rights-based epistemologies, methodologies and ethics in intersex studies. Conclusions: The human rights framework can contribute to the development of respectful, nonpathologising and reflexive research practices in intersex studies.

Session 2: Conceptualsing Intersex 2

Chaired by: Sindy Joyce | Sociologist and Member of President Higgins Council of State

Intersex-people within theological frameworks, especially the roman-catholic tradition *Katharina Mairinger | University of Vienna, Austria*
Intersex rights. Living between sexes. *Nikoletta Pikramenou | Researcher and legal expert on intersex rights, Greece*
Growing up 'round here: Considering Questions of Agency in Rural Intersex Narratives *Katelyn Dykstra | University of Manitoba, Canada In absentia*

Intersex-people within theological frameworks, especially the roman-catholic tradition

Katharina Mairinger *| University of Vienna, Austria*

My thesis deals with recognition of Intersex-people within theological frameworks, especially the roman-catholic tradition https://st-theoethik-ktf.univie.ac.at/ueber-uns/team/mairinger-katharina/
Precisely because religion is suspected of supporting discrimination against gender minorities, a theological reformulation of recognition paradigms is necessary, also because otherwise religion-based hermeneutics continue to contribute to the suppression of intersex people.

Intersexuality is a rare occurrence, nevertheless society, as well as religious communities tend to ignore it totally or even insult or violate against intersex-individuals. There are threatening anti-gender-campaigns evolving in central Europe that exert physical as well as symbolic violence on LGBTQI+ people. My thesis will show how mechanisms of symbolic power affect intersex-people on different levels of society according to Pierre Bourdieus remarks on gay-movements and suggests options against the discrimination of intersex-people, especially in the catholic religious field. First, I am going to explain the empirical insights on intersex as well as current and historical medical treatment methods in a few words. Bourdieus remarks on gay-movements will be the methodological guideline, which leads to a differentiated understanding of mechanisms of symbolic power that affect intersex-people. Furthermore, I extend these remarks on the catholic religious field in order to understand mechanisms of symbolic power within the catholic religious field itself. So my aim is to deconstruct heteronormative patterns of perception, thought and action of Roman Catholic theology and to reconstruct them in favor of a concept of recognition theory. This theory with the theologian Thomas Pröpper, who drafts a theology on the principle of freedom, which fundamentally takes every human being into consideration as an intended creation. By his distinction between the claim to freedom, which is universally valid, and the realization of freedom, which is materially and bodily bound, I show how a theology must reformulate itself from its foundations in order to recognize intersex people.

Intersex Rights. Living Between Sexes.

Nikoletta Pikramenou | *Researcher and legal expert on intersex rights, Greece*

Intersex people are born with sex characteristics that do not fit typical notions of male or female bodies, as a result of which they are stigmatised, marginalised and denied the recognition of their fundamental rights. Often, they are subjected to involuntary and harmful sex "normalising" surgeries at birth, which violate their bodily integrity, self-determination and informed consent, so as to comply with societal and legal norms. Moreover, binary legal frameworks prevent them from enjoying the rights to access to identification documents, start a family, or be free from discrimination in all areas including employment and sports. To elaborate on intersex violations that emanate from binary laws, this presentation will draw from the book "Intersex rights. Living between sexes" which was published by Springer in 2019 and introduced the first legal global study on intersex rights. In detail, the author of the book, will provide a brief overview of the situation of intersex rights in 31 jurisdictions. Those countries include: those outside of the European Union (EU) such as Kenya, South Africa, Uganda, Argentina, Chile, Colombia, United States, Australia, New Zealand, Bangladesh, India, Nepal, Pakistan, Philippines, Viet Nam and EU Member States such as Austria, Germany, Greece, Malta, Portugal, the Basque Country in Spain and Scotland in the United Kingdom,

Belgium, Denmark, Finland, Ireland, Luxembourg, Netherlands, Romania, Slovenia and Sweden. Then, based on her research findings, she will conclude that the male/female binary constitutes a source of inequalities for both those who identify with it and those who do not and will propose sexless/genderless equality through the introduction of genderless/sexless legal frameworks as the key to achieve equality for all.

Growing up 'round here: Considering Questions of Agency in Rural Intersex Narratives

Katelyn Dykstra | *University of Manitoba, Canada*

In the forward to his *Aberrations in Black: Towards a Queer of Colour Critique*, Roderick A. Ferguson reimagines a photograph of a rural scene in Manchester, Georgia, USA, super imposing onto it the queers of his memory growing up there that he argues the photo intentionally erases. This paper asks how queer theory can account for disappearing rural queers, particularly intersex people who evade the physicians touch only because of their intersecting locations as racialized, poor, and/or rural, while simultaneously doing justice to the structural inequalities evidenced by these disappearances. Rurality, socio-economic class, and race have profound impacts on the way intersex people access care, or are accessed by medical professionals, and yet intersex studies has not yet explored these intersections within discourses of representation in a sustained way.

In response to this lack, and relying on Hilary Malatino's uncovering of disappearing poor, rural, and racialized bodies in John Money's archive, and explored in their new book *Queer Embodiment: Monstrosity, Medical Violence, and Intersex Experience*, I suggest that the disappearance of intersex bodies from medical archives might not always be read as a lack or loss but as a complex and potential thriving. This suggestion demands a rethinking of rural queer studies by intersex narratives like Lucia Puenzo's *XXY*, that features a family who moves rurally to keep their intersex child safe from medicalization, and Yuhong Pang and Robert Tokanel's *She's Not a Boy*, that catalogues the life of Tatenda Ngwaru, who grew up intersex in rural Zimbabwe. The questions I raise in response to these narratives are: what does bodily autonomy look like without easy access to hospitals? What are cultural and medical approaches to intersex in rural spaces? What does rurality do to the concept of agency as it is presented intersex narratives?

Session 3: Medical Management of Intersex

Chaired by: Brenda Daly | Dublin City University

Medical Doctors as Torturers? Dutch Responses to the UN Committee Against Torture's 2017 - Reccommendations Regarding Intersex Children in The Netherlands *Gijs Hablous | Radboud University Nijmegen, The Netherlands*
"Usually the mother:" Dilation and the medical management of intersex children *Celeste E. Orr | St. Lawrence University, New York, USA* *Amanda D. Watson | Simon Fraser University, British Colombia, Canada*
Agency-based model of intersex health as part of a larger conversation on intersex rights requests in medical settings *Daniela Crocetti | Academic Intersex Ally, Italy* *Valentino Vecchietti | Independent Academic & Intersex Human Rights Activist, UK* *Surya Monro | University of Huddersfield, UK* *Tray Yeadon-Lee | University of Huddersfield, UK*

Medical Doctors as Torturers? Dutch Responses to the UN Committee Against Torture's 2017 Recommendations Regarding Intersex Children in The Netherlands

Gijs Hablous *| Radboud University Nijmegen, The Netherlands*

In 2017, the United Nations Committee Against Torture (CAT) drafted its concluding observations based on the 7th Periodic Report of The Netherlands under the Convention Against Torture. The CAT made four recommendations regarding intersex, with a specific focus on non-consensual irreversible unnecessary medical interventions performed on babies and children. It called on the Dutch government to (1) ensure that no-one is subjected to such interventions, (2) ensure access to impartial counseling services and psychosocial support for intersex children and their parents, (3) guarantee that all non-urgent irreversible interventions are postponed until the child in question can participate in decision-making, and (4) investigate instances of non-consensual medical interventions in the past and 'punish perpetrators' and make sure 'the victims are provided with redress'.

This paper provides an analysis of the responses to the CAT's recommendations from different actors within The Netherlands, including nongovernmental intersex and LGBTI organisations, members of parliament and national policy makers, and health care professionals working within DSD/Intersex expert centres. How do these actors frame the issues at stake, and what kinds of power dynamics are implicit in these frames? Between whom do responses align or diverge and how can this be explained? In order to answer these

questions, a Critical Frame Analysis (CFA) will be conducted. The data to be analysed exists of semi-structured interviews with key individuals in each of the aforementioned actor categories, as well as relevant parliamentary documents, NGO reports, press releases, and web texts. The study provides insight into norm contestation and norm dynamics of (transnational) intersex human rights norms within a national context.

"Usually the mother:" Dilation and the medical management of intersex children

Celeste E. Orr | *St. Lawrence University, New York, USA*

Amanda D. Watson | *Simon Fraser University, British Columbia, Canada*

The routine medical genital mutilation of people with intersex variations – particularly infants, children, and adolescents – has been well documented (Davis 2015; Preves 2003; Fausto-Sterling 2000; Dreger ed. 1999). However, too few studies (Karkazis 2008) critically examine intersex individuals' parents' experiences and relationships with medical professionals who "treat" their pathologized intersex children. The fact that there are so few analyses is noteworthy; intersex people often reference their parents, in particular their mothers, when recounting their experiences of medical trauma (Guillot 2017; Wall 2015; Pagonis 2015). Moreover, one of the "treatments," namely vaginal dilation, prescribed by medical professionals often falls to the mother. Hence, this paper asks: why are mothers uniquely involved in their intersex children's "treatment," and what are the implications of their involvement?

Dilation with a medical dildo-like device is intended to ensure the assigned girl child's "shallow" vagina or the surgically constructed vagina does not "close off." Emi Koyama (2003: 2) explains: "when they surgically 'create' a vagina on a child, the parent – *usually the mother* [emphasis added] – is required to 'dilate' the vagina with hard instruments every day for months in order to ensure that the vagina won't close off again." Many intersex scholars and activists refer to this practice as "ritualistic" (Koyama 2003: 2), "institutionalized" (Arana 2005: 31) sexual abuse of children (Orr 2018). Mothers understandably follow doctors' orders and become complicit in sexual abuse; and, consequently, strain or destroy their child-mother relationship (Karkazis 2008).

Mothers' involvement in dilating their assigned girl intersex children remains undertheorized. Hence, drawing from intersex, feminist, and motherhood studies scholars and attending to mothers' involvement in dilation, the authors posit that mothers are compelled to perform this traumatizing act because, (1) mothers are expected to make decisions about and "care" for their children more than fathers (Apple 2007, Baillargeon 2009, Villalobos 2014), and (2) it is assumed dilation will not be "read" as sexual assault if performed by the mother rather than the father. Given that mothers and fathers are implicitly and explicitly called upon to

perform their gender roles and, therefore, perform different childcare tasks, we need to be more attentive to combating how our culture and current "gender order" (Connell 2009: 3) cultivates an environment in which good-intentioned mothers perform dilation on their intersex children. This mutilating and abusive practice, whereby mothers become the instruments playing out harmful status quo beliefs of the medical establishment, echoes the familiar social expectation of mothers to pursue the direction of medical experts for their own good and the good of their families.

Agency-based model of intersex health as part of a larger conversation on intersex rights requests in medical settings

Daniela Crocetti *| Academic Intersex Ally, Italy*
Valentino Vecchietti *| Independent Academic & Intersex Human Rights Activist*
Surya Monro *| University of Huddersfield, UK*
Tray Yeadon-Lee *| University of Huddersfield, UK*

In this presentation we investigate requests for, and obstacles to, an agency-based model of intersex health as part of a larger conversation on intersex rights requests in medical settings. We use the term agency-based as we seek to engage with debates surrounding the social model of health that emerged in the field of disability theory. We use the lens of critical disability theory to offer thoughts on the social constructs that *still* obstacle an agency-based model of health for people with variations of sex characteristics. Due to contentious issues of bodily harm caused *by* medical treatment, and the concentration of DSD medical treatment in childhood, we have chosen to reflect on an agency-based model instead of a purely social-cultural model. The social model of health was developed in conjunction with the social model of disability in order to shift attention away from a pathological model of bodily difference towards the consideration of individual needs in the pursuit of a fulfilling life (Shakespeare et al 1996). However, this model later came under critique for being reductionist and not fully addressing embodied lived realities (Shakespeare and Watson 2002; Hosking 2008). We will discuss how intersex theorists and activists have utilized critical disability theory, adding considerations on the use of disability theory for intersex through the lens of our qualitative research. The presentation will then highlight the social factors that *continue* to inform DSD medical practice and obstacle an agency-based model of intersex health. Two clusters of cultural underpinnings of intersex medicalization were present in the interview data: cultural erasure, pathologization and body normativity; and sex binarism and heterosexism. We address these two clusters through three interconnected nodes that impact agency-based health: pathologization of body norms; a lack of adequate agency-based healthcare; and the continued application of the sex-binary in VSC medical practice.

DAY 2 | Thursday, 22nd April 2021

09:00 – 09.35 Welcome

09:35 – 10:50 Parallel Panels 4

Session 1: Intersex in The Arts

Chaired by Sophie Doherty | Dublin City University

Film vs TV: Intersex representation in Australian media

Kamran Qureshi | University of East Anglia, UK
Intersex: Crossing The Vocal Boundaries *Alexandros N. Constansis | Musicologist and Specialist Singing Voice Researcher/Consultant*
***Stands a lady on the mountain.* The inculturation of gender roles through children's rhymes and games in early 20th Century Ireland** *Carol Barron | Dublin City University, Ireland*

Film vs TV: Intersex representation in Australian media

Kamran Qureshi *| University of East Anglia, UK*

Intersex has been neglected in Australian television and especially in films. This research study produces a historical account that explores the narratives in Australian films and television and visual representation of intersex variations as a reflection of Australian society. It conducts a comparative and individual study of both film and television narratives to examine the roles these mediums have played in educating, while entertaining, viewers. It also interrogates how specific intersex issues, including medical, the use of authority in infant surgeries, either as parents or medical professionals, social and psychological problems, have been highlighted in Australian film and television. The selection criteria are fiction feature films and television drama series only. Factual programs like documentaries, news reports, interviews, and talk shows are excluded from this study.

The study offers a critical analysis of all extant Australian films and television dramas, having intersex characters, produced during the last 25 years. The author uses textual analysis as the research method to closely examine Australian fictional screen through the combination of an academic and the filmmaker's lens and gather new knowledge on the less visible issue of intersex in Australian society. In conclusion, this paper asserts that Australian television until recently has conceived intersex as freaks, villainous and supernatural and has not been conceived in other genres except crime and medical dramas. While the Australian films completely abandoned intersex subject and failed to present realistic characters with intersex variations.

Intersex: Crossing the Vocal Boundaries

Alexandros N. Constansis | *Musicologist and Specialist Singing Voice Researcher/Consultant*

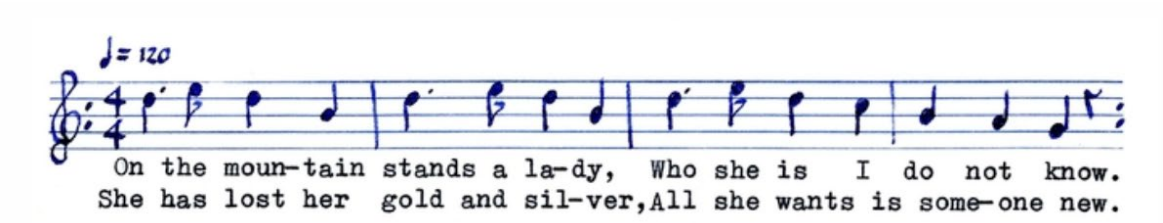
The 20th-century western music tradition mainly recognised six gender-specific vocal categories: female sopranos, mezzo-sopranos and altos and male tenors, baritones and basses. Only a few voices 'in a million', a euphemism for singers with intersex variations, such as Paulo Abel Do Nascimento, continued to surface as a reminder of the pre-20th century voice history. The changes in attitudes became so imperceptible that in the German voice classification system (Fach), with its ca. 25 distinctions, we mainly recognise high-female and low-male voices. Only two subcategories, i.e., the *Kontratenor* (Countertenor) and the Sopranist, i.e., male singers employing a falsetto technique, exist outside the boundaries of binary-gendered vocality. Other hybrid vocal personae, such as female tenors and basses, are rarely recognised. Based on Constansis (2005 & 2020), the term 'hybrid vocal personae' defines all authentic vocalists associated with variant formation.

Despite or outside the Fach limitations, new gendered or gender non-conforming (GNC) voices continue to appear. In this paper, we examine the cases and the role that intersex vocal personae play in challenging the vocal and acoustical binary. Let us hope that the future choir will entirely consist of vocal ranges beyond other categorisations. This will make us all richer in sounds and meanings.

Stands a lady on the mountain. **The inculturation of gender roles through children's rhymes and games in early 20th Century Ireland**

Carol Barron | *Dublin City University, Ireland*

Assistant Professor in Dublin City University and holds academic qualifications in anthropology, folklore, child development, and nursing. Her research interests include folk medicine, medical anthropology, children's play and games, gendered play, archival research and participatory research methodologies with children.



In the field of child lore, the conceptualization of folklore as performance and communication has led to a focus not only on the social, developmental and educational, but also on the cultural, expressive and aesthetic (Kirshenblatt-Gimblett 1976; McDowell 1979; Goodwin 1985; Beresin 1995; Roemer 1995). In particular, folklorists have focused on what Brian Sutton-Smith b termed *'the nonserious things of life'* (1970: 2). Since the 1970s these 'nonserious things' have been termed 'expressive culture'. This expressive culture, which

includes children's rhymes and games forms a significant part of children's experience of childhood and their play worlds.

This paper examines how the prevailing view of 'appropriate' gender roles were communicated and transmitted to children through the rhymes and songs of their games in 20th Century Ireland. Specifically; the societal and cultural importance of marriage for girls, the dangers of being a 'wallflower' and the role of divination in children's Halloween games in assisting them to look to future events; such as marriage.

Material for this paper comes from an examination of The Schools Collection (S.C) of 1937-1938 which is the largest single folklore collecting scheme ever undertaken in Ireland. The collection was conducted in collaboration with the Irish Folklore Commission, the Department of Education and the Irish National Teachers' Organisation. 100,000 children in 5,000 primary schools in the 26 counties of Ireland were encouraged to collect folklore material in their home districts on a wide variety of topics including their own games. The collection has 1,128 bound and paginated Volumes, with over half a million manuscript pages and over 40,000 copybooks in its collection.

Much has been written about the acquisition of gender roles, this paper looks at the ordinary, the everyday, the *'the nonserious things of life'* and argues that its power lay in its very 'ordinariness' which was largely unseen by adults.

Session 2: Intersex: New Interdisciplinary Approaches (INIA) Panel Discussion

Chaired by: Mauro Cabral Grinspan | GATE - Trans, Gender Diverse and Intersex Advocacy in Action

Introducing the Intersex: New Interdisciplinary Approaches (INIA) programme

Surya Monro | University of Huddersfield, UK

Amets Suess Schwend | Andalusian School of Public Health University of Granada, Spain

Yessica Mester | Andalusian School of Public Health University of Granada, Spain

Daria Abrosimova | University of Zurich, Austria

Adeline Berry | University of Huddersfield, UK

In 2020 an international consortium began work on a large international research programme, funded by the European Commission, to address intersex people's wellbeing and human rights from a variety of new and innovative perspectives. This programme will train a cohort of 10 early-stage researchers working collaboratively to develop knowledge that will inform policy making and practice across a range of key sectors. Using a human rights framework, the research topics are relevant to stakeholders who are concerned with supporting the wellbeing and rights of intersex people through knowledge sharing and development. Intersex people's healthcare, social and human rights issues are often overlooked. They continue to face exposure to multiple forms of human rights violations and discrimination, requiring cross-sectoral policy responses in fields including healthcare, education, and the law. INIA provides 10 innovative research projects, each of which will contribute original knowledge and research findings for use by service providers, policy makers, NGOs, advocates, and individuals with personal experience of sex variations. The INIA programme will surface multiple discourses about intersex and variations of sex characteristics, drawing on disciplines including socio- legal studies, sociology, psychology, political science, and cultural studies.
This conference session will include a brief introduction to the entire programme. This will be followed by a roundtable session in which some of the INIA researchers will present their projects and any early findings, and a chance to discuss the issues and ask questions.

Session 3: Family Experiences of Intersex

Chaired by: Michael Farrell | European Commission against Racism and Intolerance

What meaning do parents give to variations in their child's sex characteristics?

Gaëlle Larrieu | PhD candidate (Sociology) at the Observatoire Sociologique du Changement (Sciences Po), France

Where was our consent? The healthcare experiences and family dynamics across intersex peoples' life stages

Mandy Henningham | University of Sydney, Australia

Tiffany Jones | La Trobe University, Australia

What meaning do parents give to variations in their child's sex characteristics?

Gaëlle Larrieu *| PhD candidate (Sociology) at the Observatoire Sociologique du Changement (Sciences Po), France*

In France, over the last five years, there has been increasing debate about the care of children with variation in sex characteristics. Surgical operations and hormonal treatments on infants performed without their consent and without vital urgency are at the heart of these debates. These practices and the discourses that justify them make gender norms visible (Kessler, 1990; Fausto-Sterling, 2012; Gough et al., 2008; Morland, 2005). Looking at the discourses of parents of children with variation in sex characteristics allows us to question gendered body norms. We will see that "bodily normality" is the subject of gendered readings.

My paper is mainly based on in-depth semi-directive interviews with French parents of children with variation of sex characteristics. I also rely on discussions with doctors - endocrinologists and surgeons - specialists in SVD and members of associations of people concerned by these variations and/or parents, as well as on their written productions.

The first part of my work will focus on how the diagnosis of a variation of sex characteristics reveals the parents' expectations of their child's gendered body. We will see that gendered body norms are self-evident to parents and are taken for granted (West & Zimmerman, 1987). In the second part, we will show that surgery and hormonal treatments on children's bodies are thought to be a way of allowing them to partially or fully access femininity or masculinity by modifying sex characteristics deemed abnormal. Thus, these standardization operations contribute to the creation of a common standard (Winance, 2004). Finally, I will conclude by showing how variations in children's sex characteristics can contribute to the criticism and/or redefinition of the categories of normal or abnormal for parents (Landsman, 2005).

Where was our consent? The healthcare experiences and family dynamics across intersex peoples' life stages

Mandy Henningham *| University of Sydney, Australia*

Tiffany Jones *| La Trobe University, Australia*

In the last decade, people with diverse sex characteristics have been increasingly studied or referred to as part of a large umbrella group, "intersex". The United Nations has acknowledged the right to non-discrimination in healthcare for intersex youth and issued statements against practices of early surgical interventions under the context of 'child torture' and 'LGBTI youth rights' broadly (Office of the High Commissioner for Human Rights, 2015; United Nations Human Rights Council, 2014). This paper considers how health interventions for intersex youth have been recently studied in a global context of research literature. It then compares these framings to the results of a mixed-method international online survey of people with intersex variations on their retrospective experiences of surgical/medical

interventions and healthcare, and relationships with their families throughout various life stages. This study (n=81) found that most participants felt the surgery was inappropriate and that a lack of consent was a primary area of concern regarding this decision by healthcare professionals and families. Further, most participants noted they felt they had insufficient healthcare, including a lack of sufficient mental healthcare support as most services had inadequate knowledge regarding intersex matters. Participants expressed a desire for more knowledgeable healthcare providers (including mental healthcare), better long-term care and follow up, and handover process from paediatric to adult healthcare.

Some participants felt that healthcare professionals heavily influenced their parents' decisions which resulted in parents imposing and enforcing strict gender roles and behaviours, further illustrating a lack of autonomy and consent for intersex children. Many participants noted feelings of anger towards parents and three quarters of participants who found their reared gender inappropriate had poor relationships with their families. These findings highlight the relationship between authoritarian influence over family and how these combined authoritarian approaches have often resulted in a lack of bodily autonomy for people with intersex variations.

Day 2: 11:15 – 12:15 Plenary Session 3

Chaired by: Morgan Carpenter | Co-Executive Director Intersex Human Rights Australia, PhD Candidate in Bioethics, University of Sydney

Intersex Ireland

13:15 – 14:15 Plenary Session 4

Chaired by Irene Kuzemko, OII Europe

The Intersex Mapping Study at Dublin City University

Mapping the Lived Experience of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy

Tanya Ní Mhuirthile *| School of Law and Government*

Anthony Staines *| School of Nursing, Psychotherapy and Community Health*

Mel Duffy | *School of Nursing, Psychotherapy and Community Health*

Maria Feeney | *School of Law and Government*

The official title of our study is: *Mapping the Lived Experiences of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy* It is funded by the Irish Research Council.

Our work is an important step forward because at the moment, there is not enough data about people's lives to meaningfully engage in policy reform to ensure that their rights are upheld in all aspects of life and society.

We know very little about what life is like for intersex people here in Ireland. Anecdotal evidence suggest they experience higher levels of discrimination compared to the non-intersex population. Intersex people themselves and their families/partners have never been the focus of in-depth research. Nor have their doctors and other professionals who care for, and support them. We are working to address this gap in knowledge to learn more about how we can work to support this diverse and hidden population.

We are interviewing intersex people, their family members and their partners. We are also engaging with healthcare professionals to learn about what it means to be intersex and how people live with variations of sex characteristics. We also have an online survey for intersex people who may prefer to anonymously participate in our research.

PROFILES - Our Conference Delegates

A

Eva Alcántara Zavala

Degree in Psychology, Master´s degree in Women's Studies, PhD in Social Sciences, psychoanalyst, member of the Sistema Nacional de Investigadores (National System of Researchers), CONACYT - Consejo Nacional de Ciencia y Tecnología (National Council for Science and Technology), Research Professor at Universidad Autónoma Metropolitana Xochimilco, Mexico and general advisor in Brújula Intersexual.

Daria Abrosimova

After earning a degree in Sociology, Daria pursued a career in marketing research. Simultaneously, she acted as a human rights activist. She continues to pursue projects to improve medical care for intersex people in Russia. Currently, pursuing a Ph.D. at the University of Zurich on an INIA fellowship.

Kitty Anderson

Kitty Anderson is an intersex activist based in Iceland. She is the president of Intersex Iceland and Co-chair of Organisation Intersex International Europe (OII Europe). In the past she served on the Icelandic Ministry of Welfares Queer committee from 2014-2016, on the board of Samtökin 78 - The national queer organisation of Iceland from 2015-2018.

Hana Aoi

Systems Engineer, Masters in Women's Studies at UAM Xochimilco, Vivir y Ser Intersex´s founder and coordinator, and coordination of institutional linkage and research in Brújula Intersexual.

B

Claudia Balsamo

Was born in 1960, she is a dsd woman medicalized at the age of 11 and she is an intersex activist. She was one of the first members of AISIA in 2006. In 2014 she joined the intersex activism partIcipating in the Interfaceproject. In 2016 was one of the cofounders of IntersexEsiste and she is also a member of the LGBT association Agedo. She participated in several meetings of OII Europe and Ais-dsd. She parteticipated with Daniela Crocetti at the Huddersfirld conference in 2016 She identifies herself as a cis woman and she is a high school teacher.

Clara Barry

Clara Barry is an intersex activist, working primarily with ShoutOut and Intersex Ireland. Her goal is to deconstruct the dangerous myths that lead to violations of intersex people's human rights, through educating others in a non - judgemental, from - the - top format. She's a proud plant mom.

Carol Barron

Carol Barron is an Assistant Professor in DCU, Dublin and holds academic qualifications in anthropology, folklore, child development, and nursing. Her research interests include children’s play and games, gendered play, archival research and participatory research methodologies with children. Dr Barron also has a research interest in folk medicine and medical anthropology.

Adeline Berry

Adeline is an intersex and transgender researcher and board member of Intersex Ireland and SWAI. They have collaborated on an Eisner award nominated comic, owned tattoo shops in Florida and Texas, earned a black belt in Karate and a BA (Hons) Psychology from Dublin Business School. They have spoken at conferences in Stockholm, London, Limerick, Cork and Dublin on the intersection of gender, sex work and the law. Research includes "Giving Voice to Diversity in Criminological Research: Nothing About Us Without Us" with Maynooth University and "Life for Sex Workers in Ireland Under the Swedish Model of Client Criminalisation."

C

Mauro Cabral Grinspan

Mauro Cabral Grinspan is the Executive Director of GATE, an international NGO focused on trans, gender diverse and intersex issues. He also coordinates the Argentinian working group Justicia Intersex. Mauro chairs the INIA's Advisory Board, and participated in the elaboration of the *Yogyakarta Principles* and the *Yogyakarta Principles+10.*

Morgan Carpenter

Morgan is a bioethicist, co-executive director of Intersex Human Rights Australia, and an alumnus of DCU. He participated in the first UN expert meeting on human rights violations against intersex persons in 2015. He's a signatory of the Yogyakarta Principles plus 10 on international human rights law in relation to SOGI and sex characteristics and has consulted to UN institutions including the OHCHR

Alexandros Constantis

Alexandros N. Constansis started working with the singing voice in the 1980s as a performer and a music conservatoire teacher. His interest in early music and the castrati acquired a more academic focus in 1995. Since 2002-2003, the year of his gender affirmation, Constansis has been focusing on trans* and other non-binary singing personae. He has been describing all the above mentioned singers under the umbrella term 'hybrid vocal personae'. This also became the title of his 2009 doctoral dissertation (University of York, U.K).

Daniela Crocetti

Daniela Crocetti is an academic intersex ally and co-founding member of the Italian Intersex educational collective 'intersex esiste'. They have researched and published on Intersex medicalisation, the social history of gendered components of the body (such as hormones), and health activism.

Philip Crowley

Health Services Executive, Ireland

Dr Philip Crowley is the National Director for Quality Improvement in the HSE. He is a graduate of the Advanced Training Programme in Healthcare Delivery Improvement, Intermountain Healthcare Salt Lake City Utah. He is a doctor who works part-time as a GP. He worked for

five years in Nicaragua, trained in public health in Newcastle Upon Tyne and worked for 6 years as Deputy Chief Medical Officer in the Department of Health. He has been in his current post for since 2015 years and worked in the HSE since 2011.

D

Brenda Daly
Dr Brenda Daly is an Associate Professor of Law in the School of Law & Government, DCU, where she lectures on healthcare law, employment law & alternative dispute resolution. Brenda's research interests include patients' rights and health law. Brenda is the European Association of Health Law (EAHL) National Contact for Ireland, and is a member of the Northern/Ireland Health Law and Ethics Network.

Lesley Dibley
Dr Lesley Dibley is a nurse researcher with interests in stigma, phenomenology, and chronic illness at University of Greenwich. She conducts qualitative research on people's experiences of health and illness, including those of lesbian parents, of gay men and women with inflammatory bowel disease (IBD), and of stigma linked to IBD and any status of difference.

Sophie Doherty
Sophie Doherty is an Assistant Professor in the School of Law and Government at Dublin City University. Her research is broadly situated within the areas of justice, and law and humanities, with a specialism in feminist jurisprudence, law and art

Mary Donnelly
University College Cork
Mary Donnelly is a Professor of Law at University College Cork. She researches in capacity law and health law. She is the joint Chair of the HSE National Consent Policy Advisory Group and the HSE Steering Group for Implementation of the Assisted Decision-Making (Capacity) Act 2015.

Mel Duffy
Dr. Mel Duffy, DCU School of Nursing, Psychotherapy and Community Health, has pursued an active research programme using hermeneutic phenomenology as the underlying methodology. Her research interests are: (i) uncovering the lives of those who are marginalized by the institutions of society; (ii) sexuality and the workplace stemming from a deep awareness of issues relating to the LGBT community particular issues of inequality and how they may present themselves and (iii) experiences of ageing, death and dying in society.

Katelyn Dykstra
Katelyn graduated with a PhD from the University of Manitoba's Department of English, Film, and Theatre in 2018. After which, they completed a postdoctoral fellowship in the Department of Kinesiology and Recreation Management that explored the effects of life-

writing on 2SLGBTQIA* folk's ability to access care and services. They were also the Project Manager for a research project that brought genderplay workshops to rural queer youth. Since leaving academia, Katelyn has entered the role of Director of Operations at a rural non-profit that serves folks with an intellectual disability. They have continued publishing, and you can find their work on intersex in the upcoming issue of Studies in Canadian Literature, their upcoming edited collection (with Bryn Jones Square) Sex and Medicine: Intersex Studies and the Health and Medical Humanities, and the proceedings from the last IPI conference.

F

Manuela Falzone

Manuela is intersex activist, member of IntersexEsiste and AISIA. After years of silence and isolation she started speaking about her intersex condition in 2018. She early joined AISIA and in 2020 she started working with IntersexEsiste as intersex activist member. She lives in Milan and in her working life she is a physiotherapist. She identifies herself as an intersex woman.

Michael Farrell

Michael Farrell is Vice Chair of the European Commission against Racism and Intolerance and chair of its Task Force on LGBTI issues. He is a former member of the Irish Human Rights Commission and former solicitor for Free Legal Advice Centres where he represented Dr. Lydia Foy in a case which led to the Irish Gender Recognition Act.

Maria Feeney

Maria is Postdoctoral Research Officer on the Intersex Mapping Study at the School of Law and Government, Dublin City University. Her background is in sociology and education. Her special interests are: suicide and suicidal behaviour, gender, masculinties, vulnerable and disadvantaged groups and Irish society more generally.

Bella FitzPatrick

Bella FitzPatrick is the CEO of ShoutOut, a charity which provides educational programmes on LGBTQ+ inclusion. Bella has also worked with OutRight Action International in NYC conducting research and coordinating advocacy actions in the United Nations. She likes knitting.

G

Fae Garland

Fae Garland is a Senior Lecturer in Law at the University Of Manchester who has published widely on intersex rights in both academic journals and several governmental reports. She is

currently writing a Monograph (with Dr Mitch Travis) for Bristol University Press and leads a British Academy-funded project examining the impact of Malta's GIGESC Act 2015.

David Andrew Griffiths
David Andrew Griffiths is a lecturer in Sociology at the University of Surrey. His research interests include gender and sexuality studies, feminist science studies, and cultural histories of medicine and health. He is currently working on a recent and contemporary history of intersex in the UK.

H

Gijs Hablous
Gijs Hablous is a PhD candidate at the department of Political Science at Radboud University in Nijmegen, the Netherlands. He holds a master's degree in International Relations and has taken courses in Gender and Sexuality Studies and Postcolonial Theory. His current research focuses on political contestation around intersex.

Bonnie Hart
Bonnie Hart is an intersex woman, peer worker, advocate, researcher and intersex content expert at Intersexyland: An upcycled fantasy-reality land where painful pasts are harvested for their spicy shame-truffle power-treasures. Bonnie is an active member of the intersex community in Oceania, being an original signatory of the Darlington Statement in 2017.

Gráinne Healy
Dr Gráinne Healy completed her PhD at DCU in 2015 - founder and Chairwoman of Marriage Equality Ireland, she was co-director Yes Equality, the campaign which led and won the marriage equality referendum campaign in May 2015. She is co-author of 'Ireland Says Yes – How the Referendum was won' (2015), editor of 'Crossing the Threshold – The Story of the Marriage Equality Movement' (2017) and author of 'Good Practice Guide on Values Based Campaigning for Legal Recognition of Same-Sex Relationships' (Council of Europe, 2017).

Mandy Henningham
Mandy Henningham (PhD) is an Indigenous Research Fellow at the University of Sydney where she is a dedicated LGBTIQA+ advocate and researcher in sexuality, sexual health, Indigenous studies, Intersex studies, youth, and mental health in the Department of Sociology and Social Policy, Faculty of Arts and Social Sciences.

I

Laura Inter
Brújula Intersexual's Founder and CEO, Law Degree and intersex activist. Her main work consists in providing emotional support, accompaniment and information to intersex people and their families, support the creation and advise different intersex organizations in Latin America, as well as support the creation and strengthening of intersex communities in different Latin American countries.

Alesdair Ittleson
Lawyer at *interACT: Advocates for Intersex Youth*

J

Tiffany Jones
A/Prof Tiffany Jones (BCA, BEd-Hons1, PhD) is a sociologist who has researched people with intersex variations in education, health and academic literature. Her projects have been supported by the ARC, UNESCO, beyondblue, governments and other bodies. One recent project was a CIHR funded collaboration across Canada, Belgium and the UK.

Sindy Joyce
Dr Sindy Joyce is a Human Rights Defender (HRD) and member of President Michael D Higgins Council of State. She was named as one of the *'50 brilliant Irish women who inspired us in 2018'* by the Daily Edge. Her research interests include both direct and indirect forms of racism, ethnicity/identity, social/political constructions of Irish Travellers and the production of space related inequalities. Sindy won the 2014 Traveller Pride Award for Education. She is the first Mincéir in Ireland to graduate with a PhD.

K

David Keane
Dr. David Keane is Assistant Professor in Law at Dublin City University, Ireland. Dr Keane's research is in international human rights law, with a particular focus on the International Convention on the Elimination of Racial Discrimination. His books include *Caste-based Discrimination in International Human Rights Law*; and the co-edited collection *50 Years of the International Convention on the Elimination of Racial Discrimination*.

Axel Keating
Axel Keating (they/them) is a Marie Skłodowska-Curie Early Stage Researcher with the Intersex – New Interdisciplinary Approaches research network and a PhD student at the Dublin City University School of Law and Government. Their research focuses on the education on intersex traits and variations of sex characteristics in Irish and Swedish schools. Axel is a board member of interACT Advocates for Intersex Youth and is an organising committee member for the 5th International Intersex Forum.

Irene Kuzemko
OII Europe, co-founder of Intersex Russia/OII Russia, member of interACT Youth. Intersex activist since 2015.

L

Gaëlle Larrieu
Gaëlle Larrieu, PhD candidate in sociology at the Observatoire Sociologique du Changement (Sciences Po, France). My research focuses on the experiences and pathways of parents of children with variations of sex characteristics in France.

Steph Lum
Steph Lum is a PhD candidate at Dublin City University, working on INIA Project 4: Framing legislative and policy reform to improve the lived experience of intersex in Ireland and Malta. Steph is an intersex advocate, lawyer and poet from Ngunnawal country in Canberra, Australia. Steph is also passionate about the importance of sharing intersex stories and founded YOUth&I to create a space for intersex people to share writings and artwork.

M

Katharina Mairinger
Katharina Mairinger (Mag. Theol.) studied German and French philology as well as Catholic theology in Vienna. Since 2018, she has been a doctoral student at the Department of Theological Ethics at the Faculty of Catholic Theology of the University of Vienna. Research interests: intersexuality, theology of freedom, sociology of religion. She is also editor of the Catholic online blog https://y-nachten.de.

Yessica Mestre
Yessica is an early stage researcher on the INIA project and based at the Andalusian School of Public Health - University of Granada, Spain. Yessica's interest in intersex causes started in law school where she looked for the creation of awareness around the human and fundamental rights of the intersex population and their particular situations. She finished her bachelor's degree in Law and began to work in an NGO, building projects for the resocialization of victims of the Colombian armed conflict, and the recognition of the LGBTI population as independent victims of this.

Surya Monro
Surya Monro is a Professor in Sociology and Social Policy based at the University of Huddersfield, UK, email s.monro@hud.ac.uk. Surya has published substantially in the fields of gender and sexuality, notably on LGBT and Intersex issues. She is the author of *Gender Politics: Citizenship, Activism, and Sexual Diversity* (Pluto Press 2005) co-author of *Sexuality, Equality and Diversity* (Palgrave MacMillan, 2012), author of *Bisexuality* (Palgrave MacMillan, 2015), co-author of *Intersex, Variations if Sex Characteristics and DSD: The Need for Change* (University of Huddersfield 2017) and co-editor of *Queer in Africa* (Routledge 2018). She leads the Intersex: New Interdisciplinary Approaches project (INIA) in collaboration with intersex activists and academics.

N

Carlos Alberto Narváez Pichardo
Medical Surgeon. Internal Medicine Specialist, Outpatient Hospitalization Practice (private and public institutions). Professor of Medical Therapeutics. Clinical Bioethics Certificate by UNESCO-redBioetica. Brújula Intersexual's collaborator. Mexico City.

Tanya Ní Mhuirthile
School of Law and Government, Dublin City University, Ireland.
Tanya researches the impact of law on the human body. She is Principal Investigator on the IRC funded project Mapping the Lived Experience of Intersex/Variations of Sex Characteristics in Ireland: Contextualising Lay and Professional Knowledge to Enable Development of Appropriate Law and Policy and the DCU lead on the MSCA ITN project INIA Intersex: New Interdisciplinary Approaches funded by the European Commission.

Chris North
Chris is a 74-year-old intersex person and joined the intersex community four years ago. He has extensively researched his life and written a graphic novel alongside his autobiography. Chris has been a teacher, social worker and creative arts facilitator. He aims to contribute to intersex understanding and the movement for change.

O

Celeste E. Orr
Dr. Celeste E. Orr is a Professor of Gender and Sexuality Studies at St. Lawrence University. Their research is situated at the intersection of intersex, disability, and queer studies. Orr's book prospectus, *Cripping Intersex: Exorcisms and Compulsory Dyadism*, has been accepted by UBC Press. Orr's is currently finalizing their manuscript for submission.

P

Meg Peters
Meg Peters is a doctoral candidate in the Institute of Feminist and Gender Studies at the University of Ottawa, and works primarily in intersectional disability studies, examining Disability Justice as it applies to education, pedagogy, and teaching and learning at the university level.

Loé Petit
Loé Petit is a PhD student in Political Science at Université Paris VIII (France), as well as an intersex activist. After a master thesis in Gender Studies on intersex lives, their PhD research focus on intersex as a political identity, and the emergence and building of the intersex movement. They are president of RéFRI - Réseau francophone de recherche sur l'intersexuation (the French-speaking research network on intersex).

Nikoletta Pikramenou
Dr Nikoletta Pikramenou is a researcher and legal expert on intersex rights. Her book introduced the first global legal comparative study on intersex rights and it was published in 2019 under the title "Intersex Rights. Living between sexes". She is also a member-ally of Intersex Greece and has been advocating for the recognition of intersex rights in Greece and abroad.

Sara R. Phillips

Sara R Phillips is a Trans and Intersex activist working from Ireland. She is the Chair of Intersex Ireland and the Chair of the Board of Transgender Equality Network Ireland. Sara is a board member of the National Women's Council of Ireland. She is also the treasurer and board member of both the International Trans Fund in New York and Transgender Europe.

Marta Prandelli
Marta Prandelli graduated in Psychology (BSc; MSc) at the University of Padua (Italy) where she also completed a PhD in Social Sciences in November 2018. Member of Euro-PSI Network and IntersexEsiste - informal organisation of Italian intersex activists and academic allies - she investigates the beliefs systems and the family support structure inside the Italian social environment.

Q

Kamran Qureshi
Kamran is an award-winning Director and Doctoral Researcher, at the University of East Anglia. His research work on intersex includes: Austrailian, Indian, American films and TV, Transgender Act 2018, directorial experience of telemovie *Murad*, TV series *Moorat* and *Only Love Matter*

R

Michal Raz
PhD Sociology. L'ecole des Hautes Etudes en Sciences Sociales (EHESS). Centre de recherche medécine, santé, santé mentale, société (CERMES 3). Paris, France.

Eliana Rubashkyn
Eliana is a Pharmacist, an intersex advocate and a former refugee from Colombia, currently living in Aotearoa New Zealand. Thanks to her studies in public health in Taiwan, Eliana has been active assisting vulnerable communities in Aotearoa NZ and in the world during the COVID19 pandemic, utilizing her expertise with medications and vaccines in crisis settings, and her knowledge regarding pharmaceutical networks for emergency response in the global south assisting with access to life-saving medications.

S

Amets Suess Schwend
PhD Social Anthropology, MA Arts Therapies, MA/BA Sociology. Professional activity in research and training at the Andalusian School of Public Health, Granada, Spain. Their recent publications focus on trans and intersex studies, human rights, depathologisation and research epistemologies, methodologies and ethics. Member of the consortium team and supervisor in the Intersex – New Interdisciplinary Approaches (INIA) project, funded by the European Union's Horizon 2020 research and innovation programme (Marie Skłodowska-Curie grant agreement No. 859869)

Prashant Singh
Prashant Singh is a human rights lawyer from India. He currently works with Intersex Asia as Coordinator. Prashant's research interests span across SOGIESC issues, transitional justice, migration and refugee law, etc. He has been part of national and international advocacy initiatives on intersex rights in India. He has published several reports and articles on intersex rights particularly focussed on the South Asian region. He earned his primary law degree from National Law University, Punjab.

Ailbhe Smyt
Ailbhe is a long-time campaigner on feminist, LGBT and other social issues. Most recently, she played a leading role in the marriage equality referendum campaign in 2015, and was Co-Director of the Together for Yes campaign to repeal the 8th Amendment. The former founding head of Women's Studies at UCD (University College Dublin), she has published widely on feminism, gender, politics and culture. She currently serves on the Board of Directors at Age Action Ireland.

Anthony Staines
Anthony Staines is Professor of Health Systems - Centre for eIntegrated Care and School of Nursing, Psychotherapy and Community Health, Dublin City University, Dublin, Ireland. Anthony is an epidemiologist and a public health consultant whose research focuses on the uses of information in health care. He has a particular interest in child health and disability. Working closely with the Health Intelligence Unit in the Health Services Executive in Ireland, he has led a number of projects to deliver innovative health information approaches in Ireland and Europe. He teaches on programs in public health and health systems within DCU, and on digital health in an innovative national program led by the Health Services Executive. He was formerly the chair of the Irish Blood Transfusion service, and now leads St. Michael's House, one of the larger providers of services for people with Intellectual Disability in Ireland.

Rogena Sterling
I am a multi-disciplinary scholar with a background in law and human rights and co-chair of ITANZ. My key interests are intersex rights and issues, decolonising sex/gender, biopolitics of categories and statistics, and customary law. I have been writing and researching in Indigenous rights and interests in data, governance, and the environment and teaching social policy.

T

Mitchell Travis
Mitchell Travis is an Associate Professor of Law and Social Justice at the University of Leeds. His work has been published in *Legal Studies*, *Law and Society* and *Social and Legal Studies*. Alongside Fae Garland he is currently writing a new monograph on Intersex Embodiment for Bristol University Press.

V

Valentino Vecchietti
Valentino Vecchietti is an independent academic, an intersex human rights activist, a writer, and a public speaker.

W

Amanda D. Watson
Dr. Amanda D. Watson is a Lecturer in the Department of Sociology and Anthropology at Simon Fraser University. Her book, *The Juggling Mother: Coming Undone in the Age of Anxiety,* explores how mothers who appear to be frantically juggling paid and unpaid work perpetuate established social inequities of race, gender, class, and ability.

Y

Tray Yeadon-Lee
Tray Yeadon-Lee is a Senior Lecturer in Sociology at the University of Huddersfield. Their research interests include non-binary gender, LGBT, and Intersex Studies, and the sociology of identities.

Z

Kimberly Zieselman
Kimberly is an intersex woman, lawyer, author of XOXY, and Executive Director of interACT. She has 25 years nonprofit advocacy experience, participated in the UN OHCHR Expert Intersex Consultation, and is a signatory to YP+10. Kimberly consults on intersex representation and is quoted and published in a number of media outlets.

Intersex Mapping Study at DCU

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