

# **Law and Intersex in Norway; Challenges and Opportunities**

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This report was commissioned by the Division for Equality and Inclusion, The Norwegian Directorate for Children, Youth and Family Affairs.

2018

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## **Key Recommendations**

1. Defer non-therapeutic medical interventions on intersex children until the individual concerned is old enough to participate in the decision.
2. Meaningful incorporation of intersex within anti-discrimination, hate crime and hateful speech legislation by including references to 'sex characteristics'.
3. Flexible gender recognition systems rather than introduction of a third sex category.

## Executive Summary

The Norwegian Government's recent *Action plan against discrimination on the basis of sexual orientation, gender identity and gender expressions 2017-2020*, illustrates a political willingness to address intersex issues. However, in its current form, Norway's legal and political framework does not offer real, substantive protections for this group of individuals. On this background, this report investigates different state responses to intersex, with the aim to suggest how Norway can improve the legal position of intersex people.

Globally, relatively few countries have legal processes related to intersex. Section two of this report examines different state approaches to intersex, and suggests recommendations based on "best practices". Among the countries we examine, Malta has the most developed model for protecting intersex people's rights, both in a gender equality and non-discrimination perspective, and with regard to bodily integrity and self-determination in connection with medical interventions on sex characteristics. This offers a model of best practices for Norway, but must be designed to fit the Norwegian situation and legal context. In proposing options for reform, we reiterate that a model of best practice in this area contains three core elements:

1. Defer non-therapeutic medical interventions on intersex children until the individual concerned is old enough to participate in the decision.
2. Meaningful incorporation of intersex within anti-discrimination, hate crime and hateful speech legislation by including references to 'sex characteristics'.
3. Flexible gender recognition systems rather than introduction of a third sex category.

Section three of this report considers how these three elements could be included within the Norwegian context. This includes:

- Broader recommendations to defer interventions on children that are non-therapeutic before the child can participate in the decision, that also will apply to non-therapeutic medical intervention on intersex children, (preferring the terminology 'treatment that can be deferred' instead of 'medically unnecessary').
- Broader amendments to medical and ethical guidelines within Norway.
- Amendments to include 'sex characteristics' (kjønnskarakteristika) as a protected characteristic within Norway's anti-discrimination legislation, hate speech legislation and crimes that could be categorized as 'hate crime'.

While these reforms are substantive, we believe they are of fundamental importance to redressing the issues faced by intersex persons.

## Norwegian Summery

Hovedanbefalinger:

1. Utsette ikke-terapeutisk behandling overfor interkjønnbarn inntil vedkommende har tilstrekkelig alder og modenhet til å delta i avgjørelsen.
2. Inkludere grunnlaget "kjønnskarakteristika" i lovgivning om diskriminering, hatkriminalitet og hatefulle ytringer for å sørge for at interkjønnpersoner er omfattet.
3. Fleksible ordninger for å registrere juridisk kjønn fremfor å introdusere en tredje kjønnskategori.

### 1 Innledning

Denne rapporten er todelt. Den første delen vurderer hvordan ulike land ivaretar personer med interkjønn gjennom politiske og juridiske tiltak. På denne bakgrunn skisseres opp et sett med *generelle anbefalinger* om hvordan interkjønnpersoners behov og interesser kan ivaretas av nasjonale myndigheter. Rapportens andre del tar utgangspunkt i disse generelle anbefalingene, og vurderer hvordan disse best kan gjennomføres i en norsk juridisk kontekst.

Regjeringens handlingsplan mot diskriminering på grunn av seksuell orientering, kjønnsidentitet og kjønnsuttrykk 2017–2020 er et av flere eksempler på tiltak i Norge for å gi personer med interkjønn bedre beskyttelse. Imidlertid foreligger det svært lite kunnskap om deres interesser og behov, og dermed også hvordan juridiske og politiske tiltak bør utformes for å møte deres utfordringer. Denne rapporten tar sikte på å belyse foreliggende kunnskap om personer med interkjønn samt å gi anbefalinger om hvordan juridiske tiltak bør utformes.

#### 1.1 Hva er interkjønn?

Den medisinske betegnelsen for interkjønn er "forstyrrelser i kjønnsutviklingen". Dette er en samlebetegnelse for flere diagnoser som gir atypiske kjønnskarakteristikk. Tilstandene oppstår i den prenatal kjønnsutviklingen, det vil si under dannelsen av fosterets kjønnsorganer under graviditeten.<sup>1</sup> Bakgrunnen kan for eksempel være under-/overproduksjon av testosteron eller syndromer.

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<sup>1</sup> Hanger (2008) s. 576.



## 1.2 Terminologi

Det foreligger ingen konsensus om begrepsbruken. Interkjønn (på engelsk *intersex*) er det mest utbredte begrepet i menneskerettslig sammenheng, og blir derfor benyttet i denne rapporten. I en medisinsk kontekst, er det DSD (disorder of sex development) eller forstyrrelser/variasjoner i kjønnsutviklingen, som er de mest utbredte. Valg av begrep kan være kontroversielt i denne sammenheng, da noen mener at bruk av medisinske termer virker stigmatiserende.

I Norge gjenfinner en det samme skillet i begrepsbruken, samtidig som det kommer stadig flere eksempler på at DSD-teamene bruker begrepet "interkjønn" når de uttaler seg utenfor en medisinsk kontekst, for eksempel i avisartikler.

Forskning fra Nederland fant at personer med interkjønntilstander ikke bruker begrepet "interkjønn" selv, men sin spesifikke diagnose.<sup>2</sup> Vi anbefaler at diskusjoner om valg av begrep fortsetter, og særlig med involvering fra de berørte.

## 1.3 Behandlingspraksis og menneskerettigheter

Globalt finnes det ingen enighet om hva som er optimal behandlingspraksis overfor personer med interkjønn, og en ser derfor store variasjoner både mellom land og innad i land. Imidlertid foreligger det et konsensusdokument fra 2005 om behandlingspraksisen, utarbeidet av en rekke internasjonale medisinske eksperter.<sup>3</sup>

I Norge mottar personer med interkjønn helsehjelp fra spesialisthelsetjenesten ved de to flerregionale behandlingstjenestene for usikker somatisk kjønnsutvikling ved Haukeland universitetssykehus og Oslo universitetssykehus. Disse kalles DSD-team, hvor DSD står for den engelske betegnelsen *disorder of sex development*.

Hvert år fødes det fem til ti barn i Norge hvor helsepersonellet ikke kan stadfeste om barnet er en gutt eller en jente.<sup>4</sup> Ifølge den årlige rapporten fra DSD-teamene for 2016, ble 19 nye

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<sup>2</sup> Jantine van Lisdonk, Living with intersex/DSD: An exploratory study of the social situation of people with intersex/DSD (The Netherlands Institute of Social Research 2014).

<sup>3</sup> Hughes et al, Consensus statement on management of intersex disorders, Journal of Pediatric Urology (3/2006). Updated in 2016.

<sup>4</sup> [http://ous.prod.fpl.nhn.no/pasient/diagnoser-og-sykdommer/usikker-kroppslig-\(somatisk\)-kjønnsutvikling-\(disorders-of-sex-development-dsd\)](http://ous.prod.fpl.nhn.no/pasient/diagnoser-og-sykdommer/usikker-kroppslig-(somatisk)-kjønnsutvikling-(disorders-of-sex-development-dsd)). Updated in 12.1.2016.

pasienter behandlet.<sup>5</sup> Seks av dem var spedbarn, mens 19 av dem var over ti år. Helsepersonell foretar en utredning for å kjønnsbestemme barnet, og tilbyr deretter kirurgisk og medisinsk behandling dersom det anses som faglig forsvarlig. Noen interkjønntilstander er akutte og livstruende, og må behandles umiddelbart. Ved andre behandlingstiltak er den medisinske nødvendigheten mer uklar. Det er på denne bakgrunn at menneskerettighetsorganisasjoner som FN og Europarådet retter stadig sterkere kritikk mot sine medlemsland. De påpeker at interkjønn kun representerer et naturlig kjønnsmangfold, og at behandling tvert imot vil påføre barnet unødvendig skade som infertilitet, ødelagt seksualfunksjon og psykiske problemer som kjønnsidentitetsproblemer.<sup>6</sup> På denne bakgrunn mener de at behandling som ikke er medisinsk nødvendig, men som har kjønnskorrigerende eller kjønnsbestemmende formål, strider mot grunnleggende menneskerettigheter som autonomi og fysisk integritet.<sup>7</sup>

#### 1.4 Behov for en holistisk tilnærming

Forskning viser at personer med interkjønn møter ulike utfordringer i deres dagligliv, både sosialt, og i møte med helsevesen og offentlig administrasjon.<sup>8</sup> Dette begrunner behovet for en helhetlig tilnærming, hvor tiltak på ulike samfunnsfelt må sees i sammenheng. Med andre ord må ikke tiltak bare iverksettes på det medisinske feltet, men også innen utdanning, diskriminering, hatkriminalitet og registrering av juridisk kjønn.

En studie fra Nederland indikerer også at personer med interkjønn føler liten tilhørighet med LHBT-bevegelsen.<sup>9</sup> Det er derfor viktig at personer med interkjønn ikke inkluderes i tiltak på LHBT-området uten et bevisst forhold til de ulikheter som finnes mellom gruppene.

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<sup>5</sup> Årsrapport for flerregional behandlingstjeneste for usikker somatisk kjønnsutvikling 2016 (available at <https://forskningsprosjekter.ihelse.net/senter/rapport/FF-OUS-HB4/2016>, accessed 27.4.2017).

<sup>6</sup> For instance Redd Barna, LLH, Skeiv Ungdom, *Rettane til LHBTI-barn i Noreg: Vurdering og tilrådingar i lys av FN sin barnekonvensjon* (2016), Report of the UN Special Rapporteur on torture and other cruel and inhuman degrading treatment or punishment (2013), the Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (2015), OHCHR et.al., *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement* (WHO, 2014), the United Nations High Commissioner for Human Rights, *Discrimination and violence against individuals based on their sexual orientation and gender identity* (2015)

<sup>7</sup> Ibid.

<sup>8</sup> Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of people with intersex/DSD* (The Netherlands Institute of Social Research 2014).

<sup>9</sup> Ibid.

## **2 Anbefaling 1: Utsette ikke-terapeutisk behandling overfor barn med interkjønn inntil vedkommende har tilstrekkelig alder og modenhet til å delta i avgjørelsen**

### **2.1 Rettslig rammeverk**

Helsehjelp til personer med interkjønntilstander er ikke underlagt *særskilt* lovgivning, men må oppfylle de generelle krav i helselovgivningen, som for eksempel kravet til faglig forsvarlighet, jf. helsepersonelloven § 4. Kravet innebærer blant annet at helsehjelpen må være nødvendig og ha dokumentert nytte. Pasientens autonomi står også sentralt i norsk helselovgivning, og i pasient- og brukerrettighetsloven er barn gitt særskilt deltakelsesretter som øker i takt med barnets alder og modenhet.

Noen behandlingstiltak overfor personer med interkjønntilstander kan være problematisk i lys av forsvarlighetskravet, da enkelte behandlingstiltak har en uklar medisinsk indikasjon. Kunnskapsgrunnlaget for hva som er optimal behandlingspraksis er også svakt. Videre kan behandlingstiltak som utføres overfor barn som ikke kan avgi gyldig samtykke, utfordre de deltakelsesretter barn har i medhold av Grunnlovens § 104, menneskerettighetskonvensjoner og pasient- og brukerrettighetsloven.

### **2.2 Særskilt om medisinsk nødvendighet**

Et av de vanskelige spørsmålene i vurderingen av legitimiteten ved behandlingspraksisen overfor personer med interkjønn, er hvilke behandlingstiltak som regnes som *medisinsk nødvendige*. Noen behandlingstiltak har utvilsomt en medisinsk indikasjon, for eksempel hormonbehandling av personer med medfødt binyrebarksvikt (CAH) for å unngå salttap. Behandlingstiltak med formål om å kosmetisk “normalisere” vedkommende sine kjønnskarakteristika vil imidlertid være et eksempel på et behandlingstiltak som ikke har en medisinsk indikasjon, og som derfor bør utsettes inntil barnet kan delta i avgjørelsen. Andre behandlingstiltak er det vanskeligere å vurdere om formålet er medisinsk eller ikke.

Kirurgisk fjerning av indre kjønnsorganer foretas ved noen interkjønntilstander med økt kreftrisiko, og kan medføre infertilitet. Disse behandlingstiltakene har derfor blitt omtalt som kontroversielle, og blant annet har FN og Europarådet uttalt at kreftrisikoen ikke er

tilstrekkelig dokumentert.<sup>10</sup> Vi understreker at både kreftrisiko og tidspunktet for operasjon må vurderes grundig, da den kan lede til infertilitet og nødvendiggjør livslange hormonbehandling.

Det er positivt at de norske DSD-teamene har uttrykt en mer tilbakeholden praksis, blant annet til Dagbladet vinteren 2017 og i et brev til Helse- og omsorgsdepartementet fra 2016.<sup>11</sup> I dette brevet står det blant annet at DSD-teamene ikke har utført noen behandlingstiltak på psykososial indikasjon overfor barn mellom 2013-2015. Vi anbefaler at dette også reflekteres i ulike veiledere og retningslinjer for behandlingstjenesten. I arbeidet med en slik oppdatering bør det også foretas en vurdering, så langt det lar seg gjøre, av hvilke behandlingstiltak som har en medisinsk indikasjon og hvilke som foretas på en psykososial indikasjon.

## 2.3 Hvordan implementere anbefalingen om å utsette behandlingstiltak som ikke er medisinsk nødvendige?

### 2.3.1 Redefinere hva som er medisinsk nødvendig

På et generelt grunnlag, kan det være utfordrende å vurdere hvilke behandlingstiltak som er medisinsk nødvendige og hvilke som ikke er det. Som nevnt, foreligger det lite forskningsbasert kunnskap. En annen grunn til at det kan være vanskelig, er fordi en kategorisering av et behandlingstiltak som medisinsk unødvendig kan gi assosiasjoner til at behandlingen er ulovlig eller illegitim. I realiteten er det ingen automatikk i at behandlingstiltak som ikke har en medisinsk indikasjon er ulovlige. Det er viktig at personer med interkjønn som *frivillig ønsker* behandlingstiltak uten medisinsk indikasjon, for eksempel kosmetisk klitorisreduksjon, får adgang til dette.

Et mer hensiktsmessig utgangspunkt enn spørsmålet om hva som er medisinsk nødvendig, er formuleringen i lovbestemmelsen i Malta *om behandlingstiltak som kan utsettes*. I stedet for å vurdere medisinsk nødvendighet, rettes fokuset heller på tidspunktet for behandlingen. Det

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<sup>10</sup> For example the Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (2015), OHCHR et.al., *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement* (WHO, 2014), the United Nations High Commissioner for Human Rights, *Discrimination and violence against individuals based on their sexual orientation and gender identity* (2015).

<sup>11</sup> This was stated in a joint letter by the DSD-teams in Oslo and Bergen to the Ministry of Health and Care services from September 2016. The letter was a response to a Ministry Inquiry where they, among other questions, asked how many surgeries that were carried out on children based on psychosocial indication versus medical-somatic indication between 2013 and 2015. In Dagbladet 8.2.2017, available at <http://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>, accessed 28.4.2017.

viktigste i denne sammenheng er å unngå at barn utsettes for unødvendige og irreversible behandlingstiltak uten deres samtykke, samtidig som muligheten til å få kosmetisk eller annen "normaliserende" tiltak beholdes for dem som ønsker dette.

### 2.3.2 Bør det innføres et lovforbud?

Til tross for at de aller fleste menneskerettighetsaktører på feltet anbefaler lovforbud mot behandlingstiltak som kan utsettes, er det kun Malta som har innført dette.<sup>12</sup> Spørsmål i denne sammenheng er om og hvordan Norge kan gjennomføre en slik anbefaling.

På helseområdet har Norge tradisjon for *generelle* helselover i stedet for å lovregulere de enkelte helsetjenestene. Å innføre en lov eller forskrift om en forholdsvis liten helsetjeneste samsvarer derfor ikke godt med den norske lovsystematikken. I tillegg kan det være problematisk å innføre et lovforbud med eventuelle sanksjoner som i praksis kun vil omfatte svært få helsepersonell. Et alternativ til lovregulering er Chiles løsning, hvor medisinske retningslinjer med menneskerettighetsperspektiv er utarbeidet. En fordel med nye eller oppdaterte retningslinjer er at helsepersonell og andre berørte kan delta mer direkte i utformingen. I tillegg tillater formatet mer detaljerte redegjørelser enn lovformatet, for eksempel beskrivelse av caser. Dette er hensiktsmessig med tanke på at sakene på dette området ofte kan være komplekse.

I Chile skal de medisinske retningslinjene følges opp med lovregulering. I en norsk kontekst er det også mulig å innføre *både* oppdaterte medisinske retningslinjer og lovregulering. Fordelen med et lovforbud som i Malta er at det gir personer med interkjønn en sterk rettslig beskyttelse ved medisinske og kirurgisk behandling. I tillegg innfris de klare anbefalingene fra menneskerettighetsorganisasjoner fra FN og Europarådet. På bakgrunn av at DSD-teamene har kommunisert en mer tilbakeholden holdning med å behandle tilstander som ikke har en klar medisinsk indikasjon, fremstår ikke behovet for lovforbud like klart. Dersom en lovregulering skal innføres på lengre sikt, anbefales det at denne omfatter utsettelse av behandlingstiltak uten medisinsk indikasjon mer generelt, uten å avgrense seg til kun behandling av personer med interkjønn.

### 2.3.3 Oppdatering av medisinske retningslinjer

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<sup>12</sup> Se del 2 (komparativ del) for mer informasjon.

Vi anbefaler at medisinske retningslinjer utformes eller oppdateres av et bredt sammensatt utvalg som har kunnskap innen felt som medisin, etikk og juss. Det er viktig at personer med interkjønn har mulighet til å bli inkludert i arbeidet. Forholdet til menneskerettigheter og spørsmål om hvilke behandlingstiltak som kan utsettes, bør være sentrale vurderinger i arbeidet.

#### *2.3.4 Etiske vurderinger i behandlingsavgjørelser*

Vi understreker betydningen av etikk i vurderinger av konkrete behandlingsavgjørelser. Et tiltak kan være å gi kliniske etikkomiteer en sentral rolle i denne sammenheng. Inklusjon av slike komiteer kan for eksempel nedfelles som en fast prosedyre i vanskelige saker, blant annet i saker som omhandler barn. Et annet tiltak kan være å inkludere etikere innad i DSD-teamene, eller å ha etikere tilknyttet teamene.

#### *2.3.5 Informert samtykke*

Selv om barn med interkjønn skal overføres raskt til et av DSD-teamene for utredning, er det viktig at foreldre får tid og ro til å treffe veloverveide avgjørelser om barnet skal behandles. Forskning indikerer at måten helsepersonell informerer om barnets tilstand har stor betydning for om foreldre ønsker at barnet behandles eller ikke.<sup>13</sup> Det er derfor viktig at informasjonen er korrekt og objektiv. Det er positivt at DSD-teamene omtaler tilstandene som en naturlig kjønnsvariasjon, slik som i artikkelen i Dagbladet fra vinteren 2017.<sup>14</sup>

#### *2.3.6 Behov for mer forskningsbasert kunnskap*

Det er behov for mer forskningsbasert kunnskap for å klargjøre hva som er optimal behandlingspraksis. Etablering av et kvalitetsregister vil også være svært nyttig for å kunne kvalitetsforbedre helsetjenesten. Et nordisk register kan også være hensiktsmessig, ettersom datagrunnlaget i Norge er lite. I tillegg bør forskning se mer generelt på situasjonen for personer med interkjønn på andre felt enn det medisinske, for å belyse eventuelle andre behov og interesser.

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<sup>13</sup> For instance Streuli, Jürg C., Vayena, Effy, Cavicchia-Balmer, Yvonne og Huber, Johannes, *Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development*, Journal of Sexual Medicine, 10 (8), 2013, at 1956.

<sup>14</sup> In Dagbladet 8.2.2017, available at <http://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>, accessed 28.4.2017.

### **3 Anbefaling 2: Inkludere grunnlaget "kjønnskarakteristika" i lovgivning om diskriminering, hatkriminalitet og hatefulle ytringer for å sørge for at interkjønn-personer er omfattet**

#### **3.1 Anti-diskrimineringslovgivning**

En felles likestillings- og diskrimineringslov ble vedtatt sommeren 2017, og vil trå i kraft 1.1.2018. Loven samler de fire særlovene på diskriminerings- og likestillingsområdet, deriblant lov om forbud mot diskriminering på grunn av seksuell orientering, kjønnsidentitet og kjønnsuttrykk, som er mest aktuell i denne sammenheng. Et av grunnlagene som er beskyttet mot diskriminering er "kjønnsuttrykk", og skal ifølge lovens forarbeider også omfatte personer med interkjønn.<sup>15</sup> Dette videreføres i den nye loven.<sup>16</sup>

Det er positivt at forarbeidene eksplisitt nevner personer med interkjønn. Imidlertid beskrives grunnlaget "kjønnsuttrykk" i forarbeidene på en måte som gjør den mindre relevant for personer med interkjønn. Forarbeidene definerer kjønnsuttrykk som måten kjønnsidentiteten bevisst eller ubevisst uttrykkes eller oppfattes av andre, for eksempel med stemme, klær, kroppsspråk, sminke eller frisyre.<sup>17</sup> Vi mener det er en risiko for at personer med interkjønn ikke vil identifisere seg med grunnlaget "kjønnsuttrykk" og dermed ikke vil påberope seg beskyttelse mot diskriminering. På denne bakgrunn anbefaler vi at det innføres et begrep som tydeligere refererer til kroppslige karakteristikk, for eksempel "kjønnskarakteristika" eller "kjønnsvariasjoner".

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<sup>15</sup> Barne- og likestillingsdepartementet, Prop. 88 L (2012–2013) Kapittel 16.1.2 "Med *kjønnsuttrykk* menes hvordan kjønnsidentiteten bevisst eller ubevisst uttrykkes eller oppfattes av andre, for eksempel med stemme, klær, kroppsspråk, sminke eller frisyre".

<sup>16</sup> Barne- og likestillingsdepartementet, Prop.81 L (2016-2017), Lov om likestilling og forbud mot diskriminering (likestillings- og diskrimineringsloven) p. 313

<sup>17</sup> Se fotnote 16.

### 3.2 Hatkriminalitet og hatefulle ytringer

I Norge er ikke hatkriminalitet et juridisk begrep i lovgivningen, men det er flere bestemmelser i straffeloven som forbyr handlinger som i praksis vil utgjøre hatkriminalitet. Hatefulle ytringer er imidlertid lovregulert, blant annet i straffeloven § 185. Vår vurdering er at personer med interkjønn ikke har tilstrekkelig beskyttelse mot hatkriminalitet og hatefulle ytringer i straffeloven, da ingen av de lovregulerte grunnlagene for beskyttelse relaterer seg til kjønnskarakteristika eller kjønnsvariasjoner. Vi påpeker at LHBTI-personer generelt har liten rettslig beskyttelse i straffeloven, men ser positivt på at det pågår flere arbeider for å oppdatere lovgivningen.

Tilsvarende som for diskrimineringslovgivningen anbefaler vi at det innføres et begrep som tydeligere refererer til kroppens fysiske kjønnskarakteristika, for eksempel "kjønnskarakteristika" eller "kjønnsvariasjoner".

### **4 Anbefaling 3: Fleksible ordninger for å registrere juridisk kjønn fremfor å introdusere en tredje kjønnskategori**

"Mann" og "kvinne" er de to juridiske kjønnskategoriene i Norge. Det er positivt at den nye loven om endring av juridisk kjønn fra 2016 tillater personer med interkjønn å endre juridisk kjønn. For personer med interkjønn er dette mulig på ethvert alderstrinn, såfremt nærmere vilkår innfris. Det er blant annet et vilkår om at barn under 6 år med interkjønn dokumenterer sin DSD-tilstand for endring av juridisk kjønn. Selv om det kan være problematisk å medikalisere en prosess som i hovedsak kun har administrative følger, mener vi det er avgjørende at foreldre kun endrer barnets juridiske kjønn når barnets kjønnsidentitet avviker fra det juridiske kjønn. Vi mener derfor at det bør være et krav som relaterer seg til dette, slik som i Sverige.<sup>18</sup>

Helsepersonell har plikt til å melde inn barnets kjønn som mann eller kvinne til Medisinsk fødselsregister innen en måned etter utskriving.<sup>19</sup> Vi anbefaler at det bør være fleksible ordninger for innmelding av kjønn i situasjoner hvor barnets kjønn er uavklart.

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<sup>18</sup> Se punkt 3.3. i rapporten.

<sup>19</sup> Jf. forskrift om 21. desember 2001 nr. 1483 om innsamling og behandling av helseopplysninger i Medisinsk fødselsregister.



# 1 INTRODUCTION

## 1.1 The Aims of the Report

This report will provide an overview of existing laws and legal processes related to intersex in Norway, relevant countries in Europe and Australia. Other countries are included in the report where they are considered relevant to Norway for comparison purposes. The report contains an overview and assessment of existing legislation, legal processes and recommendations for further development in Norway. The report clarifies the possible challenges and opportunities of intersex people in Norway to claim their rights, both in a gender equality and non-discrimination perspective, and with regard to bodily integrity and self-determination in connection with medical interventions on sex characteristics.

The Norwegian Government's recent *Action plan against discrimination on the basis of sexual orientation, gender identity and gender expressions 2017-2020*, illustrates a political willingness to address intersex issues.<sup>20</sup> However, due to the lack of knowledge about the needs and interests of Norwegian intersex people, it is not clear how political and legal actions should be developed to effectively secure and protect their rights. To examine how intersex can be included in a meaningful way within the Norwegian political and legal arenas, section two of this report considers the approaches adopted in other states. Building on this, section three sets out the current Norwegian national context to explore how the core elements of a model of best practice could and should be integrated into Norway in light of its particular political, cultural and legal frameworks. Fundamentally then, this report sets out an action plan for Norway by proposing a series of reform proposals that aim to offer greater rights and protections for intersex people in Norway. This section now sets out the terms of use within the report by providing an overview of the types of issues faced by intersex persons.

## 1.2 What is Intersex?

Intersex is a term that encompasses a wide range of bodily diversities that at the anatomical, hormonal or chromosomal level gives the individual a combination of what is typically considered as “male” and “female” sex characteristics. Therefore, intersex people are not a

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<sup>20</sup> Barne- og likestillingsdepartementet, *Regjeringens handlingsplan mot diskriminering på grunn av seksuell orientering, kjønnsidentitet og kjønnsuttrykk 2017–2020*. Comments to the action plan in Section 3.

homogenous group and intersex variances can differ greatly between individuals.<sup>21</sup> Some intersex variations are discovered when a newborn baby's sex cannot be determined based on its physical sex characteristics. However, many people do not know of their intersex characteristics until puberty, later in life or may never know.

There are different definitions of intersex, and they seem to vary depending on whether one has a medical or non-medical perspective of intersex. For this reason, figures vary over the incidence of intersex. An example is that some studies do not always include intersex variations such as Hypospadias. However, when all possible variations are taken into account, studies have demonstrated that as many as two per cent of the population are intersex with 1-2 in 1000 infants receiving 'corrective' genital surgeries.<sup>22</sup> The prevalence of intersex people in Norway is also uncertain, because there is no systematic registration of intersex persons that are born or undergo treatment. Nevertheless, the Norwegian DSD-teams (the health care teams that specialize in treating intersex people) estimate that approximately 5-10 children are born with so-called "ambiguous" sex characteristics every year.<sup>23</sup> These numbers do not give the full picture, as they do not take account of cases where intersex variances are discovered later in life.<sup>24</sup> According to Diseth (2008), approximately 300 children are born with various degrees of atypical sex characteristics every year and in 10-12 cases the sex characteristics are so ambiguous that the sex cannot be determined immediately after birth.<sup>25</sup> These figures would indicate around 1 in 200 children are born with an intersex variation with 1 in 6000 children triggering medical intervention upon birth. These numbers illustrate that there is a wide spectrum of natural bodily variations, and that only a small percentage of them are diagnosed and possibly treated. According to the yearly report from the DSD-teams, 19 new patients were treated in 2016.<sup>26</sup> Six of them were neonates, while thirteen of them were over ten years old.

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<sup>21</sup> Including, for example, partial androgen insensitivity syndrome, androgen insensitivity syndrome, congenital adrenal hyperplasia, Klinefelter syndrome, ovo-testes, Swyer syndrome and Turner syndrome.

<sup>22</sup> Blackless, M., Charuvastra, A., Derrtyck, A., Fausto-Sterling, A., Lauzanne, K., & Lee, E. (2000). How sexually dimorphic are we? Review and synthesis. *AMERICAN JOURNAL OF HUMAN BIOLOGY*, 12(2), 151-166. See also A. Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Identity* (Basic Books, 2000), at 76.

<sup>23</sup> [http://ous.prod.fpl.nhn.no/pasient/diagnoser-og-sykdommer/usikker-kroppslig-\(somatisk\)-kjønnsutvikling-\(disorders-of-sex-development-dsd\)](http://ous.prod.fpl.nhn.no/pasient/diagnoser-og-sykdommer/usikker-kroppslig-(somatisk)-kjønnsutvikling-(disorders-of-sex-development-dsd)). Updated in 12.1.2016.

<sup>24</sup> Some intersex conditions are usually discovered later, often in puberty, for instance when a girl does not menstruate.

<sup>25</sup> Trond H. Diseth, Children born with ambiguous genitalia, *Tidsskrift for den norske legeforening* (5/2008) at 5

<sup>26</sup> Årsrapport for flerregional behandlingstjeneste for usikker somatisk kjønnsutvikling 2016 (available at <https://forskningsprosjekter.ihelse.net/senter/rapport/FF-OUS-HB4/2016>, accessed 27.4.2017).

### 1.3 Terminology

There is no consensus on which term to use when referring to this group. However, intersex is the most commonly used term by advocacy groups, human rights organizations and supranational bodies such as the United Nations and the Council of Europe.<sup>27</sup> The fact that much national and international legal reform has been instigated by patient-advocates has meant that intersex has been the term preferred in most legal documentation. For these reasons, intersex is the term preferred in this report.

In the medical field, the term *disorder of sex development* (DSD) is the prevailing term.<sup>28</sup> This term has been criticized, especially by intersex and human rights actors, who highlight that the term *disorder* stigmatizes and pathologizes natural bodily variations.<sup>29</sup> One of the main arguments is that the medical term "disorder" fails to acknowledge that many of the difficulties faced by intersex people are caused by rigid societal and institutional understandings of binary sex rather than inherent problems of intersex variance.

Similarly, in Norway, there is no consensus on which term to use when referring to this group. Echoing the global medical profession, the Norwegian DSD-teams mostly use *disorder of sex development* ("forstyrrelser i kjønnsutviklingen") although there are examples of representatives from the DSD-teams using the term "intersex" (interkjønn)<sup>30</sup> In governmental responses, the terminology is not consistent and we see different terms in use.<sup>31</sup> In Norway, there is no common patient organization for people with various intersex

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<sup>27</sup> For instance Redd Barna, LLH, Skeiv Ungdom, *Rettane til LHBTI-barn i Noreg: Vurdering og tilrådingar i lys av FN sin barnekonvensjon* (2016), Report of the UN Special Rapporteur on torture and other cruel and inhuman degrading treatment or punishment (2013), the Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (2015), OHCHR et.al., *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement* (WHO, 2014), the United Nations High Commissioner for Human Rights, *Discrimination and violence against individuals based on their sexual orientation and gender identity* (2015).

<sup>28</sup> Hughes et al, Consensus statement on management of intersex disorders, *Journal of Pediatric Urology* (3/2006) on 148-162.

<sup>29</sup> Terms such as *variations of sex development*, *differences of sex development*, *atypical sex development* or both *intersex/DSD* are examples, and can typically be found in governmental reports and policies, where a more neutral language may be preferable. An example is when the German Ethics Council examined intersex issues in 2012, and chose to use the abbreviation DSD, which both refers to *disorder* or to *difference* of sex development. Det tyske etikkrådet (2013) p. 11. In this report we continue to use the term intersex as the terminology of choice for patient advocates whose experience we privilege over and above medical professionals.

<sup>30</sup> Robert Bjerknes, Anne Grethe Myhre, Helge Ræder og Hilde Bjørndalen, *Feil i somatisk kjønnsutvikling* (last revision 2016), Trond H. Diseth, Children born with ambiguous genitalia, *Tidsskrift for den norske legeforening* (5/2008) at 5. The DSD-teams also use similar terms such as *uncertain/unclear sex development or sex characteristics* ("usikker kjønnsutvikling/kjønnskarakteristika", "genitale misdannelser", "forstyrrelser i kjønnsutviklingen» eller "feil i den somatiske kjønnsutviklingen"). Examples of the use of "interkjønn" (intersex) are found in <https://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>, accessed 15.9.2017.

<sup>31</sup> In the government's action plan, the word "interkjønn" is used, which is a direct Norwegian translation of "intersex". In the legal framework, more specifically in the Gender Recognition Act (lov om endring av juridisk kjønn), the term *unclear/uncertain sex development* is used ("usikker somatisk kjønnsutvikling").

conditions, but there are some organizations for specific patient groups that use the specific diagnosis and not intersex.<sup>32</sup> Research from Lisdonk (2014) also demonstrates that the persons concerned do not use the term intersex, but their specific diagnosis.<sup>33</sup> We would stress the need to further engage in broad debates on which term to use, and to include all relevant actors such as patient and human rights organizations and medical personnel. Based on the knowledge we have, we will use the term intersex (interkjønn) and the sex characteristics associated with intersex variance, as these have, internationally, been the terms preferred by intersex advocates and within human rights discourse.

Another challenge to note is around the terminology of "gender" and "sex". In Norwegian gender and sex are both translated as "kjønn". When examining global state responses to intersex, it can be confusing when both gender and sex are translated into "kjønn".

## 1.4 Medical Interventions and Human Rights

In the absence of sufficient data and consensus on optimal treatment, the practices vary between professionals. For instance, health personnel are divided on the question of whether sex correction or assignment surgeries should be delayed until the child is mature enough to give informed consent.<sup>34</sup> Important work was carried out in 2005 in a consensus meeting in Chicago on management of intersex conditions, with over 50 international medical experts reviewing and revising the medical guidelines.<sup>35</sup> These professionals recognised the need to halt such medical interventions on the basis of the 'welfare of the child.' However, it is unclear whether the Chicago Consensus statement has actually reduced the number of non-therapeutic medical interventions. Although there have been important revisions to current medical guidelines, international bodies such as the UN and the Council of Europe report that intersex children are still regularly subjected to medical and surgical intervention to assign them as male or female.<sup>36</sup> While it is important to work with the medical profession in order

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<sup>32</sup> For instance the patient organization for persons with CAH, that uses their specific diagnosis, and not intersex, see <http://cah.no/dette%20er%20cah.html>, accessed 15.9.2017.

<sup>33</sup> Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of people with intersex/DSD* (The Netherlands Institute of Social Research 2014).

<sup>34</sup> For instance, the Finnish Pediatric Surgeon Mika Venhola that denounces corrective surgeries on intersex infants and children, see <https://interactadvocates.org/finnish-pediatric-surgeon-denounces-intersex-surgeries/>, accessed 15.9.2017.

<sup>35</sup> Hughes, I. A., Houk, C., Ahmed, S. F. og Lee, P. A., «Consensus statement on management of intersex disorders», *Journal of Pediatric Urology*, 2 (3), 2006, 148-162. Updated in 2016.

<sup>36</sup> For example Council of Europe Commissioner for Human Rights, *Human rights and intersex people*, Strasbourg 2015, United Nations Special Rapporteur Against Torture Juan E. Méndez, Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development. (GE.13-10577), Eliminating forced, coercive and otherwise involuntary sterilization. OHCHR, UN WOMEN, UNAIDS, UNDP, UNFPA, UNICEF AND WHO, (UN interagency statement 2014).

to instigate changes in practice, we would stress the need for common discussions between the medical community and intersex voices. In a Norwegian context, the intersex-symposium organized in 2016 is a good example, where actors from the medical field, patient organizations, public sector and civil society met to discuss needs and interests of intersex people.<sup>37</sup>

Medical practices that surgically or hormonally alter children without their consent for non-therapeutic reasons have been widely condemned by international intersex organisations, other NGOs as well as international and regional human rights bodies. Thirteen UN bodies including the United Nations Committee against Torture and the United Nations Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment,<sup>38</sup> have criticised non-consensual genital surgery and other unnecessary interventions on intersex children as being “harmful practices”, “violation[s] of integrity” and “inhuman treatment”.<sup>39</sup> Moreover, the Council of Europe has criticised such “medically unjustified violations of children’s physical integrity” and has committed to ensuring that “that no-one is subjected to unnecessary medical or surgical treatment that is cosmetic rather than vital for health during infancy or childhood, guarantee[ing] bodily integrity, autonomy and self-determination to persons concerned”.<sup>40</sup> The UN bodies have deemed non-consensual, non-therapeutic genital surgeries on intersex children to be a breach of Article 19 United Nations Convention on the Rights of the Child (UNCRC) which provides that States must take “all appropriate ... measures to protect the child from all forms of physical or mental violence, injury or abuse ... while in the care of parent(s), legal guardian(s) or any other person who has the care of the child” (Article 19).

Intersex issues have also been increasingly put forward by Norwegian LGBTI and human rights actors, and denounce so-called “sex normalizing” treatment performed on intersex

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<sup>37</sup> Organized by the Directorate for Children, Youth and Family Affairs, here referred to by the organization for Klinefelter <http://klinefelter.no/innhold/nyheter/symposium-om-variasjon-i-kroppslig-kjoennsutvikling.aspx>, accessed 15.9.2017.

<sup>38</sup> CEDAW, CAT, SRH, SRT, WHO, OHCHR, UNICEF, UN Women, UNAIDS, UNDP, UNFPA, CRPD, CRC, COE

<sup>39</sup> CAT/C/DEU/CO/5, Committee against Torture, Concluding Observations on Germany, 12 December 2011, para. 20

[http://www.institut-fuer-menschenrechte.de/fileadmin/user\\_upload/PDF-Dateien/Pakte\\_Konventionen/CAT/cat\\_state\\_report\\_germany\\_5\\_2009\\_cobs\\_2011\\_en.pdf](http://www.institut-fuer-menschenrechte.de/fileadmin/user_upload/PDF-Dateien/Pakte_Konventionen/CAT/cat_state_report_germany_5_2009_cobs_2011_en.pdf) UN Special Rapporteur on torture and other cruel, inhuman or degrading treatment or punishment, 1 February 2013, para.77

<sup>40</sup> Council of Europe Parliamentary Assembly, Resolution 1952 Children’s right to physical integrity, 2013 <<http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-en.asp?fileid=20174&lang=en>> (accessed 07/12/2016). See also Council of Europe Parliamentary Assembly, Recommendation 2023 Children’s right to physical integrity, 2013 <http://assembly.coe.int/nw/xml/XRef/Xref-DocDetails-EN.asp?FileID=20176&lang=EN> (accessed 07/12/2016).

children without their consent.<sup>41</sup> Norwegian DSD-teams have recently outlined a more careful and balanced medical approach to treat intersex people that purports to meet these human rights standards.

In this process, it is important to examine legal reforms that can secure the rights to bodily integrity based on best practices from abroad, as well as examining how intersex people are granted legal protections in other fields. A comparative analysis of how other countries have approached these issues is therefore important in order to determine whether similar laws or policies should be implemented in Norway.

## 1.5 The Need for Holistic Protection

Research has highlighted that intersex people face difficulties in their relations with other people; while they generally have a clear gender identity, they are afraid that others do not perceive them as "completely" male or female.<sup>42</sup> Studies have reported that intersex individuals feel a sense of shame, low self-esteem and fear of negative reactions.<sup>43</sup> Moreover, research has highlighted that intersex people generally do not identify with the LGBT-movement which they view as being more about sexuality and gender identity than sex.<sup>44</sup> It can therefore be problematic that policy makers often integrate intersex people as the "I" in different LGBTI-policies without sufficiently acknowledging the differences between these groups. Nevertheless, there are some similarities between the groups, which might make joint actions beneficial, namely that LGBTI people challenge social perceptions of sex and gender identity. We welcome initiatives addressed to LGBTI-people, but stress the importance that special attention is paid to the interests and needs that are unique to intersex-people. This will require a holistic approach that not only addresses concerns with regards to surgical and medical interventions, but also includes reforms in the areas of education, anti-discrimination laws, hate crime laws and also gender markers in ID papers. Most fundamentally, it will

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<sup>41</sup> Kirsten Sandberg, The Rights of LGBTI Children under the Convention on the Rights of the Child, *Nordic Journal of Human Rights*, (4/2015) on 337-352, Kirsten Sandberg, *Interkjønnbarn*, Tidsskrift for familierett, arverett og barnerecht (4/2016), Redd Barna, LLH, Skeiv Ungdom, *Rettane til LHBTI-barn i Noreg: Vurdering og tilrådingar i lys av FN sin barnekonvensjon* (2016), debates in newspapers such as <https://www.dagbladet.no/kjendis/hanne-28-ble-utsatt-for-operasjoner-som-ikke-var-medisinsk-nodvendig---det-ble-et-traume-pa-grunn-av-det-de-gjorde/66908547> and <https://www.dagbladet.no/kultur/norge-bryter-med-fns-barnekonvensjon/66922729> accessed 15.9.2017.

<sup>42</sup> Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of people with intersex/DSD* (The Netherlands Institute of Social Research 2014).

<sup>43</sup> Ibid., Schweizer et al. *Gender Identity and Coping in Female 46, XY Adults With Androgen Biosynthesis Deficiency (Intersexuality/DSD)*, *Journal of Counseling Psychology*, (1/2009) at 189-201.

<sup>44</sup> Jantine van Lisdonk, *Living with intersex/DSD: An exploratory study of the social situation of people with intersex/DSD* (The Netherlands Institute of Social Research 2014).

require a reframing of the term ‘medically necessary’ to ensure that non-therapeutic interventions on intersex variations do not occur on children until they are old enough to give valid consent.

## 2 THE COMPARATIVE ANALYSIS

This chapter focuses on relevant jurisdiction and legal processes outside Norway, before being returned to in the following chapter. In doing so, chapter 2 draws on and evaluates a range of different global responses to intersex issues to consider which responses are most effective for enhancing the protection of intersex people. Largely, responses can be categorized into three themes: those that protect bodily integrity, those that recognise an intersex status and those that do not recognise intersex issues at all.<sup>45</sup> In this section, the report will first address how some states have protected the bodily integrity of intersex people and then consider state responses that have recognised intersex status through a variety of methods, including anti-discrimination law, hate crime legislation and gender markers other than male or female in official documents. Finally, this section will consider what core elements are required to create a model of best practice in terms of reform. Thus, this section will set out three key recommendations for States to follow if they wish to offer intersex persons meaningful and effective protections. Chapter 3 shall then consider these recommendations in light of the Norwegian context by exploring Norway's current socio and legal context and considering how (if at all) it needs to be amended to meet these three recommendations.

### 2.1 Protections of Bodily Integrity

The fundamental concern of the intersex community is to stop medically unnecessary<sup>46</sup> treatments on intersex minors. Despite these calls for legal protections and the international condemnation of such medical practices by international bodies such as the UN and the Council of Europe,<sup>47</sup> only three countries so far have initiated state responses to restrict (in varying degrees) unnecessary and non-consensual medical interventions on intersex children; Malta, Columbia and Chile.<sup>48</sup> Each of these jurisdictions offers varying degrees of protection for bodily integrity, with the most comprehensive protections coming from Malta.

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<sup>45</sup> Garland F and Travis M (2018) *Legislating Intersex Equality: Building Resilience for Intersex People through Law*.

<sup>46</sup> "Unnecessary" has been defined here as medical intervention made on the basis of aesthetics or normativity.

<sup>47</sup> *Europarådets Menneskerettighetskommisær (2015)*. Europarådets Menneskerettighetskommisær, *Human rights and intersex people*, Strasbourg 2015

<sup>48</sup> Although note that Chile's Ministry of Health has issued guidance to the medical profession to stop medically unnecessary genital surgeries on intersex infants while legal frameworks are developed.



None of the Nordic jurisdictions have specific provisions that sufficiently protect the bodily integrity of intersex individuals. However, Iceland is currently working on a law on gender identity and sex characteristics with a holistic approach based on the “Maltese” model. Sweden also has a specialized law on legal and physical change of gender/sex under revision, which has separate provisions for intersex persons, and in both Finland and Sweden the national ethics councils have played an important role in enhancing ethical aspects concerning treatment and other issues (see section 3.1.2.3). Denmark currently has no specific regulation concerning intersex.<sup>49</sup>

### 2.1.1 Comprehensive Protection

#### *Malta*

Malta is the only State that offers comprehensive protection over the bodily integrity of intersex children, and we would recommend that Norway also initiate actions that prevent non-therapeutic medical and surgical procedures without the informed consent of the intersex person. In 2015, Malta’s *Gender Identity, Gender Expression and Sex Characteristics Act* (GIGESC) introduced a holistic body of reforms designed to offer a range of protections to intersex individuals. Alongside provisions that now allow individuals to self-ascribe their own gender identity;<sup>50</sup> extend ‘hate crime’ legislation to incorporate sex characteristics and also set out sex characteristics as a protected category within its anti-discrimination law (these will be considered below);<sup>51</sup> s 14 GIGESC states that:

*It shall be unlawful for medical practitioners or other professionals to conduct any sex assignment treatment and/or surgical intervention on the sex characteristics of a minor which treatment and/or intervention can be deferred until the person to be treated can provide informed consent.*<sup>52</sup>

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<sup>49</sup> <http://www.ft.dk/samling/20151/almindel/suu/spm/862/svar/1355451/1683340/index.htm>; <http://www.ft.dk/samling/20142/almindel/suu/bilag/44/1543760.pdf>.

<sup>50</sup> Section 4 Gender Identity, Gender Expression and Sex Characteristics Act 2015 allows individuals to change official records of their gender without any medical evidence being required to do so.

<sup>51</sup> Section 4 allows individuals to request change in first name and recorded gender to reflect self-determined gender. No medical evidence is necessary. Section 10(3) amends Article 83B of the Maltese Criminal Code to include offences motivated on the basis of gender expression and sex characteristics. Section 14 Gender Identity, Gender Expression and Sex Characteristics Act 2015 prohibits any discrimination on the basis of sexual orientation, gender identity, gender expression and sex characteristics’ discrimination.

<sup>52</sup> Section 14 GIGESC Act 2015.

Thus Malta specifically prohibits unnecessary and cosmetic sex assignment treatment and surgeries on minors. This approach has been heralded by the intersex community as being “a beacon of hope” and a model of good practice in terms of legal reforms.<sup>53</sup> By placing bodily integrity at the centre of reforms, commentators and critiques have commended Malta for “*enacting real protections for our community ...*”<sup>54</sup> which “recognis[e] the legitimacy of the corporeal experiences of these individuals.”<sup>55</sup> Decoupling legal regulation from the medical narrative of intersex enables individuals to more fully integrate and participate in society.<sup>56</sup> It places decisions surrounding surgery and gender identity in the hands of the individual rather than in the hands of parents or medical professionals.

However, while Malta has received widespread praise for its approach, it is not without criticism and there are some concerns that these provisions lack ‘teeth’: doctors who choose to ignore s14 will face a small fine and possible repercussions from their professional body.<sup>57</sup> Critical legal appraisals such as Garland and Travis are therefore concerned that the Act is only symbolic in its operation and may not actually prohibit surgeries in practice. While the long-term effects of s14 are yet to be seen, the authors are concerned that surgeries may continue to take place, and thus believe that Malta’s legislation does not offer full protection to intersex children. To increase the legal protection of intersex people, legal sanctions should be attached to such provisions. Moreover, the Act lacks any extra-terrestrial jurisdiction and thus there is no mechanism to prevent parents from taking their children abroad to have surgeries in jurisdictions that do not prohibit such practices. The impact of these oversights could be significant in practice and mean that children may still be subjected to intersex genital surgeries and hormonal treatment without their consent. Any legislation must consider ways in which to protect children from being taken to other jurisdictions to have surgeries and hormonal treatment performed.<sup>58</sup> An ideal approach would see the medical profession and legislators working in harmony to support the rights, interests and autonomy of intersex people. Medical guidelines and legislation in isolation may be ineffective.

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<sup>53</sup> Respondent 11. Garland and Travis (2018).

<sup>54</sup> Garland Travis, Respondent 8.

<sup>55</sup> Garland and Travis (2018).

<sup>56</sup> Garland and Travis (2018).

<sup>57</sup> Garland and Travis (2018).

<sup>58</sup> Such an approach can be found in the UK’s Female Genital Mutilation Act 2003 for example.

## *Iceland*

Currently, the Nordic jurisdictions do not have specific provisions in place that sufficiently protect the bodily integrity of intersex people. Malta is the only jurisdiction thus far to integrate such comprehensive protections. However, Iceland is currently working towards a similar framework. The Icelandic Ombudsman for children issued an opinion in 2015 concerning treatment on intersex children. Their clear recommendation is that intersex children should make their own decisions on surgery and hormonal treatment when they have reached sufficient age and development to make an informed decision. Unnecessary and irreversible interventions go against the rights of the child. The government has recently issued a taskforce to examine different ways of tackling intersex issues. The initiative is to make an action plan relating to LGBTI, and is, at the time of writing, still being developed. It has a holistic approach that includes issues such as discrimination, hate crime, treatment and third sex categories, but it also proposes provisions that will protect bodily integrity and self-determination on the grounds of sex characteristics.

### 2.1.2 Partial Protections

#### *Columbia*

Unlike Malta's State response, it is the Constitutional Court of Columbia (Columbia's highest Court) that has partially restricted the ability of both parents and the medical profession to consent to cosmetic intersex genital surgeries and hormonal treatments on children.<sup>59</sup> This is one of the few Courts in the world to have issued an opinion on this matter, and the only one to enhance the protection of intersex minors by placing limitations on parental consent.<sup>60</sup> In 1995, the Columbian Constitutional Court heard a case that involved a petitioner whose penis had accidentally been damaged at infancy. His parents had subsequently consented to the boy's surgical reassignment as female. The petitioner was contesting this assignment stating that he had never assumed a 'female' identity. The Court ruled that parents are unable to consent to genital surgery in certain circumstances. As a result of this decision, surgeons that worked on intersex children were unsure as to whether genital normalizing surgeries were in

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<sup>59</sup> Sentencia No. SU-337/99; Sentencia No. T-551/99. These cases are reported in Spanish. See Julie A. Greenberg & Cheryl Chase, Colombia's Highest Court Restricts Surgery on Intersex Children, at <http://www.isna.org/colombia/background.html> (last visited 14 Dec 2016) for an English summary. See also <http://escholarship.org/uc/item/3kj8q07x>.

<sup>60</sup> Contrast for example with the recent Australian decision in *Re: Carla (Medical procedure)* [2016] FamCA 7 (20 January 2016) which has ruled that a family can consent to gender normalising surgery that results in the sterilisation of their child without the Court's consent. See <https://oii.org.au/31036/re-carla-family-court/> for an in-depth case summary.

fact legal following this decision. Consequently, in 1999, two cases came before the Court where doctors were recommending genital surgery and the parents were seeking the court's authority for these surgeries to go ahead.<sup>61</sup> During the proceedings, the Court recognised that intersex people were a minority entitled to anti-discrimination protections and that corrective surgeries potentially violated their autonomy and bodily integrity.<sup>62</sup> Given the lack of information that parents have about intersex, the fact that intersex often is portrayed as a 'disease to be cured',<sup>63</sup> the Colombian Court decided that an enhanced form of parental consent was needed to ensure that surgeries were in the best interests of the child rather than to 'normalise ... strange beings'.<sup>64</sup> The Court therefore demanded that parental consent must be "qualified and consistent" and thus must meet certain conditions to ensure that parents were not acting on their own fears, but on the best interests of a child:

1. "Consent must be in writing;
2. Information provided must be complete. The parents must be informed about the dangers of current treatments, existence of other paradigms, and the possibility of delaying surgeries and giving adequate psychological support to the children;
3. The authorisation must be given on several occasions over a reasonable time period to ensure the parents have enough time to truly understand the situation."<sup>65</sup>

The Court also ruled that parents cannot consent for children over five years old as at that point, the child had achieved a sufficient level of autonomy and developed their gender.<sup>66</sup> While this marked a progressive move towards protecting the bodily autonomy of children and is certainly an improvement on allowing parents the unfettered ability to consent surgery, this offers only partial protection as parents may still make decisions about surgery without the consent of the child. Where Malta fully respects children's right to bodily autonomy, the Colombian Court still places decisions in the hands of the parents and thus non-consensual surgeries may still take place. Moreover, while the Court has attempted to ensure that parents are making well rounded decisions based on the best-interests of the child, it does not prohibit normalising surgeries and nor does it consider other forms of medical interventions such as

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<sup>61</sup> An earlier decision in 1995 had left the doctors concerned about liability for performing intersex genital surgery. See Greenberg (2012) *Intersexuality and the Law: Why Sex Matters*, New York, New York University Press at 36 – 37 for more.

<sup>62</sup> See Noa Ben-Asher (2006) "The Necessity Of Sex Change: A Struggle For Intersex and Transsex Liberties" Vol 29 *Harvard Journal of Law & Gender* 52 – 98, footnote 76.

<sup>63</sup> Julie Greenberg (2012).

<sup>64</sup> Greenberg (2012) 36

<sup>65</sup> *Ibid* 37.

<sup>66</sup> Noa Ben-Asher (2006), footnote 76.

hormonal treatments that intersex children may undergo. Thus we would recommend that parents should not be able to consent to any form of normalising medical treatments for intersex minors. Furthermore, treatment should be delayed until a child is able to consent them. While the age that a child can consent to medical treatment is the subject of much debate, we would recommend in the short term to bring this in line with other areas of Norwegian Law which currently recognises the age of full legal capacity as 18, but 16 for health issues as a main rule where decisions are capable of being deferred for this amount of time. In the UK, capacity to consent to medical treatment is done on a case-by-case basis without reference to a particular age – such an approach may put undue pressure on children and young adults to conform to decisions made by their families or by medical professionals. This would need to be reviewed to ensure that children are not pressured into surgeries. Conversely, a balance needs to be struck with children who seek access to medical interventions that delay the onset of puberty where they require them.

### 2.1.3 Interim Protections

#### *Chile*

While Chile does not yet have any legal protections in place for intersex minors, Chile's Sub-secretariat of Public Health issued "Instructions on Aspects of Health Care to Intersex Children" in December 2015.<sup>67</sup> These instructions specifically call doctors to stop performing 'normalising' surgeries on intersex children. These instructions are designed to be an interim measure while Chile reviews its legal frameworks to bring in more coherent legal protections centred on the bodily integrity of intersex infants.<sup>68</sup> The actions of the government demonstrate clear leadership on the rights of intersex children and send a powerful message to the medical community in relation to how intersex children should be treated. However, the authors of this report question whether such guidance is sufficient to protect the bodily integrity of children. A recent study conducted by Garland and Travis which interviewed intersex activists across the West (including Iceland and Sweden)<sup>69</sup> demonstrate that legal interventions are of fundamental importance to changing medical practices. Respondents in this study believed that there must be clear economic and legal consequences in place to be able to effectively challenge the medical community. As one respondent in their study stated,

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<sup>67</sup> Circular 8, 22 December 2015, entitled "*Instructions on aspects of health care to intersex children*". See <https://oji.org.au/30250/chilean-ministry-stops-normalising/>.

<sup>68</sup> See <https://oji.org.au/wp-content/uploads/2016/01/Circular-08-22.12.15-Instruye-Sobre-Ciertos-Aspectos-de-la-atencion-de-Salud-a-Ninos-y-Ninas-Intersex.pdf> and also Morgan (11 January 2016). "[Chilean Ministry of Health issues instructions stopping 'normalising' interventions on intersex children - OII Australia - Intersex Australia](#)". Retrieved 26 June 2016.

<sup>69</sup> The term 'activists' also included support groups and education workers.

“... if it doesn’t have any teeth, it’s a waste of time.” Garland and Travis (2018) contend that mere guidance will not be sufficient to change medical practices, and that legal sanctions are central components to instigate this change. An ideal approach would see the medical profession and legislators working in harmony to support the rights, interests and autonomy of intersex people. Medical guidelines and legislation in isolation may be ineffective.

Medical guidelines should be issued in conjunction with legislation to ensure a comprehensive protection of intersex people's right to bodily integrity. However, this must be considered in light of factors such as Norway's legal system, ongoing processes and other particularities unique to Norway.

## **2.2 Status-Based Protections**

### **2.2.1 Anti-Discrimination**

Whilst bodily integrity remains the ‘gold standard’ of intersex law reform, other legal approaches have attempted to accommodate intersex people. The introduction of anti-discriminatory provisions and/or hate crime provisions and/or third gender markers on passports or birth certificates are grouped together by Garland and Travis as ‘status-based protections’.<sup>70</sup> Currently Malta is the only jurisdiction to introduce status-based protections in combination with the protection of bodily integrity, although Iceland is also considering similar reforms. States that only use a status-based approach have been described by much of the international intersex community as failing to offer substantive, real protections and thus failing to prioritise the specific needs of the intersex community.<sup>71</sup> Consequently, status-based provisions need to be part of a series of reforms that complement reforms around bodily integrity.

Nevertheless, status-based approaches can offer greater protections in the day-to-day lives of intersex individuals. Intersex people can face heightened levels of discrimination in the workplace, schools and other social arenas. The United Nations Committee on Economic, Social and Cultural Rights for example, have noted that: “persons who are transgender, transsexual or intersex often face serious human rights violations, such as harassment in schools or in the workplace.”<sup>72</sup> As Travis (2014) notes in his article ‘Accommodating Intersexuality in European Union Anti-Discrimination Law’ these types of law offer three

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<sup>70</sup> Garland and Travis (2018).

<sup>71</sup> Garland and Travis (2018).

<sup>72</sup> UN CESCR, General Comment No. 20: Non-discrimination in Economic, Social and Cultural Rights, 2009, para32.

key benefits. Firstly, anti-discrimination laws offer protection for these individuals and symbolic recognition by the state. Secondly, the burden of proof placed on the discriminator uncouples intersex embodiment from its medicalised history. Third, the use of anti-discrimination law is ‘opt-in’ rather than a mandatory category determined by the state or the medical profession.

Forthcoming research by Garland and Travis, however, indicates that the global intersex community believe anti-discrimination law to be a secondary concern after prohibition of non-therapeutic surgeries performed on the bodies of children. While anti-discrimination can instigate broader policy changes in areas such as education, a focus on anti-discrimination law is easier than this prohibition and may be seen as a ‘quick fix’ by policy makers as it mirrors similar concerns in the broader LGBT community. As a result, we believe it is fundamentally important that anti-discrimination law forms only *one part* of a *series of reforms* to protect intersex individuals.

#### *2.2.1.1 Incorporating Intersex Into Anti-Discrimination Laws*

Many States have just used anti-discrimination law as a way to tackle inequalities faced by intersex people.<sup>73</sup> As aforementioned, however, schemes that only focus on status-based reforms will not on their own address the material concerns of the intersex community; namely bodily integrity. Nevertheless, it is a useful tool to combat daily discrimination. The ways in which States have attempted to include intersex within anti-discrimination provisions are varied.<sup>74</sup>

#### *2.2.1.2 Incorporating Intersex Within ‘Sex’*

Some jurisdictions, such as South Africa, have amended sex discrimination law to include intersex.<sup>75</sup> The incorporation of intersex through legislation allows for clarity as to how the judiciary are to interpret these cases. Such an amendment is not a necessity for incorporating intersex as it could be developed through case law, as Travis (2014) argues in his analysis of

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<sup>73</sup> See also Jersey, South Africa’s Anti-discrimination provisions in South Africa’s *Judicial Matters Amendment Act 2005* South Africa is currently hearing “The Prevention and Combating of Hate Crimes and Hate Speech Bill 2016” which defines hate crime as including crime motivated on the basis of sex, and the bill clearly defines under s 3 that ‘sex’ includes ‘intersex’.

<sup>74</sup> See also *Human rights and intersex people* (2015) pp. 44 - 46.

<sup>75</sup> South Africa’s *Judicial Matters Amendment Act 2005*.

European Union anti-discrimination law.<sup>76</sup> However, unless intersex is specifically mentioned in legislation it has the possibility of being ignored, misunderstood or overlooked within case law.

### 2.2.1.3 *Incorporating Intersex Within ‘Gender’ Identity/Expression*<sup>77</sup>

Others States like Finland and Sweden have included intersex within its definition of gender identity/gender expression. Finland, for example has recently revised its Act on Equality between Men and Women to prevent discrimination on the basis of gender identity and gender expression.<sup>78</sup> Now s3(5) provides that “This act’s provisions on discrimination based on gender identity or gender expression apply correspondingly to discrimination based on the fact that an individual’s physical gender-defining characteristics are not unambiguously female or male.” These revisions are designed to extend protection to both intersex and trans individuals. However, there are fundamental concerns with this approach, particularly because it conflates issues of gender with sex. This challenge may be avoided in the Norwegian context given that ‘gender’ and ‘sex’ are not distinguished.

Similarly, Sweden includes ‘intersex’ within its understanding of gender expression. Sweden has one anti-discrimination law (the Swedish Discrimination Act) which explicitly mentions non-conforming gender identities or expressions (“könsöverskridande identitet eller uttryck”) as a prohibited ground of discrimination.<sup>79</sup> While similar concerns are raised in relation to the conflation of gender and sex, it could be more effective to have encompassed intersex people within the definition of sex characteristics (rather than identities or expressions) instead. Moreover, the term ‘non-conforming’ can be seen as stigmatizing. The Swedish Ombudsman for Equality has decided not to use the term non-conforming when referring to discrimination on the basis of gender expression, even though this is the wording of the law.<sup>80</sup> Instead they only use the term “gender identities or expressions” (“könsidentitet eller uttryck”).

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<sup>76</sup> This is how, for example, trans people were originally included in EU anti-discrimination law. See for example *P v S and Cornwall County Council* (1996) C-13/94 ECR I-2143.

<sup>77</sup> See also *Human rights and intersex people* (2015) pp. 44 - 46.

<sup>78</sup> Laki miesten ja naisten välisestä tasa-arvosta (Gender Equality Act, Finland).

<sup>79</sup> Original text: “1 § Denna lag har till ändamål att motverka diskriminering och på andra sätt främja lika rättigheter och möjligheter oavsett kön, könsöverskridande identitet eller uttryck, etnisk tillhörighet, religion eller annan trosuppfattning, funktionsnedsättning, sexuell läggning eller ålder”.

<sup>80</sup> Available at <http://www.do.se/om-diskriminering/skyddade-diskrimineringsgrunder/konsidentitet-och-konsuttryck-som-diskrimineringsgrund/#1> accessed 24.1.2017. We are not aware of any intersex people raising cases about discrimination in Sweden, though there have been several cases of discrimination of trans people on the basis of gender expression.



#### 2.2.1.4 An Intersex-Specific Ground<sup>81</sup>

One of the best attempts at introducing intersex into anti-discrimination law has been in Australia where an intersex-specific ground has been introduced.<sup>82</sup> The Sex Discrimination Amendment (Sexual Orientation, Gender Identity and Intersex Status) Act (Cth) 2013 introduced intersex as a possible ground for anti-discrimination. It stated that:

(1) For the purposes of this Act, a person (the ***discriminator***) discriminates against another person (the ***aggrieved person***) on the ground of the aggrieved person's intersex status if, by reason of:

- (a) the aggrieved person's intersex status; or
  - (b) a characteristic that appertains generally to persons of intersex status;
- or

(c) a characteristic that is generally imputed to persons of intersex status; the discriminator treats the aggrieved person less favourably than, in circumstances that are the same or are not materially different, the discriminator treats or would treat a person who is not of intersex status.

(2) For the purposes of this Act, a person (the ***discriminator***) discriminates against another person (the ***aggrieved person***) on the ground of the aggrieved person's intersex status if the discriminator imposes, or proposes to impose, a condition, requirement or practice that has, or is likely to have, the effect of disadvantaging persons of intersex status.

The Australian legislation is a good example of anti-discrimination law as it puts the burden of proof on the discriminator to show that they have not discriminated. It also de-medicalises this area as the aggrieved individual does not have to prove their intersex status for the law to be effective due to the reference to 'imputed characteristics.' Language is therefore a fundamentally important requirement in terms of drafting this legislation, as the legislation may need to cover all individuals who may fall under the term intersex and individuals who are not intersex but are discriminated on the basis of a perceived intersex trait. Research has demonstrated that many individuals do not publically wish to identify as intersex and often go

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<sup>81</sup> See also *Human rights and intersex people* (2015) at p. 45.

<sup>82</sup> Garland and Travis (2018).

to great lengths to conceal this fact even from close friends and family.<sup>83</sup> Consequently, anti-discrimination that offers protection on the grounds of an ‘intersex status’ may inadvertently exclude such individuals who do not publically identify as intersex. While Australia’s reference to ‘intersex status’ could consequently be exclusionary, the Act clearly includes discrimination made on the basis of characteristics that appertains/are generally imputed to persons of intersex status under ss 5(1)(b) and (c). This ensures that all intersex individuals are included within the protections offered by anti-discrimination legislation.<sup>84</sup>

Malta also has a good example of anti-discrimination legislation which does not refer to ‘intersex status’ at all. Rather, s 13(2) GIGESC refers to discrimination/harassment made on the basis of ‘sex characteristics’ as well as gender identity and gender expression.<sup>85</sup> While Iceland’s anti-discrimination provisions do not provide protections on the basis of sex characteristics,<sup>86</sup> thus excluding intersex from such protections, its planned reform options are to include protections from discrimination (and hate crimes) made on the basis of gender identity, gender expression and sex characteristics.<sup>87</sup>

The authors of the report feel that ‘sex characteristics’ (kjønnskarakteristika) may be a more helpful term to use when drafting anti-discrimination law in Norway to ensure it has broad coverage. Such a definition protects the congenital characteristics associated with intersex rather than framing intersex experience as an identity.<sup>88</sup> Moreover, it is crucial that intersex status is not defined as a form of transgender identity (see below).

### 2.2.2 Hate Crime

As with other minority groups, intersex people and people thought to be intersex can be the victims of hate crime. Robust legislation to protect individuals from these types of crime is needed. Consequently, some jurisdictions have hate crime and hate speech provisions to

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<sup>83</sup> Garland and Travis (2018).

<sup>84</sup> See, for example, Garland and Travis (2018).

<sup>85</sup> Greece has also used the term ‘sex characteristics’ in its recently amended anti-discrimination law (24<sup>th</sup> Dec 2015)

<sup>86</sup> Sexual orientation, gender identity and sex characteristics are also excluded from the Human Rights Chapter of Iceland’s constitution. Universal Periodic Review for Iceland Written joint submission from stakeholders: Samtökin ’78 The National Queer Organisation [www.samtokin78.is](http://www.samtokin78.is). Page 2. Available [https://www.upr-info.org/sites/default/files/document/iceland/session\\_26\\_-\\_november\\_2016/js2\\_upr26\\_isl\\_e\\_main.pdf](https://www.upr-info.org/sites/default/files/document/iceland/session_26_-_november_2016/js2_upr26_isl_e_main.pdf) (accessed 19/01/2017).

<sup>87</sup> Garland and Travis (2018)

prevent intersex individuals from criminal acts motivated on the basis of hate.<sup>89</sup> Once again, the language used to include intersex within legislation is important. A poor example of including intersex people in hate crime legislation comes from Scotland with the Offences (Aggravation by Prejudice) (Scotland) Act 2009 s2(8), which defines intersex as a type of ‘transgender identity’. Although this legislation attempted to be inclusive, it demonstrates a fundamental misunderstanding of intersex issues by conflating their issues with trans by merely incorporating intersex into the definition of gender identity (similar to Finland’s approach above). Malta has a better approach whereby s 11(2) GIGESC expands Malta’s hate crime law to include “offences motivated by gender expression and sex characteristics”. Iceland is also considering the introduction of hate crime and hate speech offences made on the basis of gender expression, gender identity and sex characteristics.

Currently, none of the Nordic Countries have specific hate crime legislation encompassing intersex people. Consequently, we believe that intersex people do not enjoy sufficient legal protection from acts of violence and hate. Thus, we would recommend that the wording should be broader and include, for instance, “sex, sexual orientation, gender identity and sex characteristics.” We would recommend a more comprehensive hate crime law in the longer term.

### 2.2.3 Third Markers on Official Documents

Another way in which States have recognised intersex ‘status’ is through the use of third markers on official documents like passports, birth certificates and social security numbers.

#### 2.2.3.1 *Passports and/or Identity Cards*

Forthcoming research by Garland and Travis has highlighted that most of their intersex respondents (speaking on behalf of a range of intersex organizations) would not engage with the opportunity to identify as ‘X’ on their passports. Predominantly, this is because most intersex people identify as either male or female. A small minority of intersex individuals would like the opportunity to identify as ‘X’ on their passports. We see no objection to

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<sup>89</sup> South Africa is currently hearing “The Prevention and Combating of Hate Crimes and Hate Speech Bill 2016” which defines hate crime as including crime motivated on the basis of sex, and the bill clearly defines under s 3 that ‘sex’ includes ‘intersex’.

allowing a third category of legal sex on passports, but would note that this is neither a priority, nor strictly an intersex issue.

Australia's Department for Foreign Affairs and Trade recognised 'X' as an official third sex on passports in 2003. Legally, this had been allowed by the International Civil Aviation Organisation since 1945 after the mass migration of the Second World War. The Australian provision has allowed individuals to engage with this category on an 'opt-in' basis. There is no mandatory obligation to identify as 'X' for intersex people. Indeed, the majority of intersex people identify as male or female, not as a third category. This type of provision, therefore, has largely been used by people who are not intersex.

The Australian position is still problematic as it relies upon the approval of a medical practitioner or psychologist.<sup>90</sup> This continues to medicalise intersex experiences. Moreover, the Department for Foreign Affairs and Trade's guidance to LGBTI travellers notes that those with 'X' on their passport may encounter difficulties in other jurisdictions due to its infrequent usage. Since 2013 it has also been possible to choose 'X' on Danish passports without requiring medical documentation. This would avoid the medicalization of intersex experiences. However, we would still stress that third markers should not be used automatically for intersex due to aforementioned concerns of 'outing' and stigmatisation, but rather for any individual who wishes to identify as 'X'. 16 year old children should be allowed to decide this for themselves, or younger if they have reached a sufficient age and maturity. Another possible solution, and one the authors would prefer, is to remove gender/sex markers from official documentation altogether.

### *2.2.3.2 Birth Certificates and Social Security Systems*

Similar to the concerns mentioned above, having a third marker on a birth certificate (even in the form of a blank space) for intersex people may lead to stigmatisation. For example, Germany has been criticised for its introduction of a third sex into its law in 2013 through the Law amending Personal Rights Regulations Personal Status Law Amending Law - PStRÄndG (Gesetz zur Änderung personenstandsrechtlicher Vorschriften Personenstandsrechts-Änderungsgesetz—PStRÄndG). Intersex organizations have largely

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<sup>90</sup>Australian Passport Office (2017) Sex and Gender Diverse Passport Applicants  
<https://www.passports.gov.au/passportsexplained/theapplicationprocess/eligibilityoverview/Pages/changeofsexdoborpop.aspx>  
4.1.2018

disapproved of this legislation.<sup>91</sup> The following criticisms identified by Garland and Travis are particularly important for the intersex community:

1. Introducing a third sex fails to protect children from unnecessary non-therapeutic surgical interventions.
2. A third sex does not take into account that sex is a spectrum.
3. Children should not be placed into a category of legal sex other than male or female. Children should not be at the forefront of societal battles to reorganise sex and gender.
4. The possibility of being placed into a third sex category may encourage parents and medical professionals to have surgery at an earlier stage rather than discouraging it.
5. The legislation does not provide a method to leave the category of intersex once entered into it.

Moreover, there are concerns that the German approach effectively places the decision in the hands of the medical profession and that this approach results in the “forced outings” of minors whose sex is ambiguous.<sup>92</sup> Other interest groups may want a third category of sex on birth certificates (for example non-binary trans individuals). This report offers no comments on the merits of this, other than to say that a category of third sex on birth certificates should not be justified on the basis of intersex embodiment.

While there are concerns around the implications of a third marker on birth certificates, there is a need for flexibility on birth certificates so that it is possible for children to amend their birth certificates if they want to.<sup>93</sup> In Malta, it is possible for children to self-determine their gender identity. While minors cannot apply to amend their birth certificate themselves until they reach 18, persons exercising parental authority over the minor can make an application

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<sup>91</sup> Hida Vilorio (2013) Germany's Third-Gender Law Fails on Equality. <https://www.advocate.com/commentary/2013/11/06/op-ed-germany's-third-gender-law-fails-equality> *Zwischengeschlecht* (2013) "Intersex: Third Gender in Germany" (Spiegel, Huff Post, Guardian, ...): Silly Season Fantasies vs. Reality of Genital Mutilations <http://stop.genitalmutilation.org/post/Intersex-3rd-gender-in-Germany-Silly-season-fantasies-vs-reality-of-genital-mutilations>.

<sup>92</sup> See *Human Rights and Intersex People* (2015); D. C. Ghattas (2013), Human Rights between the Sexes: A preliminary study in the life of inter\* individuals, Heinrich Böll Stiftung: Publication Series on Democracy, Vol. 34, pp. 35-36; German Federal Anti-Discrimination Agency (FADA) (2013), Press Release: “European roundtable on the civil status law of trans\* and intersex people”.

<sup>93</sup> Garland and Travis (2017).

on their behalf to change the minor's recorded gender and/or first name.<sup>94</sup> Where it is not possible to determine the sex/gender of the minor, it need not be listed on the birth certificate until the child reaches 18.<sup>95</sup>

Some Nordic jurisdictions allow for a third sex/gender in certain circumstances. For example, the Finnish social security system operates with female and male categories, but in cases of intersex, a temporary social security number can be given. For historical reasons, the temporary social security number contains an even last number that signifies a female sex, but can be changed if needed. If an intersex person later wants to correct their social security number to match the correct gender, this can be done by delivering a doctor's statement of a wrong sex assignment at birth, and the office will correct the social security number denominator. This continues to medicalise intersex experience.

## **2.3 The Core Elements Essential for a Model of Best Practice: General Recommendations**

### **2.3.1 Recommendation 1: Prohibiting Non-Therapeutic Medical Interventions on Intersex Children Until the Individual Concerned Is Old Enough to Give Informed Consent**

Malta's legal prohibition of providing treatment that can be deferred, offers the best approach in regards to protect the bodily integrity of intersex individuals. By prohibiting medical and surgical treatment based on aesthetic values and normativity on intersex minors, this provision answers the most important issue for intersex people. Our recommendation is therefore that Norway put in place legislation that ensures that intersex people are not treated unnecessarily and without consent. Here the Norwegian government must be clear: 'unnecessary' medical interventions are those interventions which are non-therapeutic. As a main rule, 16-year-old children can decide health care decisions. Nevertheless, this must be decided on a case by case assessment. As the different treatment procedures are very different, for instance hormonal treatment and invasive surgery, the age limit on 16 years can be heightened and lowered depending on factors such as the specific nature of the treatment and the child's maturity. It is preferable that the child and the parents make the decisions

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<sup>94</sup> Section 7 GIGESC. While considering an application to change recorded gender and/or first name, the Court must ensure that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration; and that due weight is given to the views of the minor (taking into account their age and maturity).

<sup>95</sup> Section 7(4) GIGESC.

together. While interim medical guidelines (as in Chile) will go some way to achieve this, it may be best to use a mixture of legislation and medical guidelines to ensure that the state, the law and medical professionals are all working towards ensuring the best possible outcomes for intersex people by supporting their autonomy.

### 2.3.2 Recommendation 2: Meaningful Incorporation of Intersex Within Anti-Discrimination, Hate Crime and Hateful Speech Legislation by Including References to ‘Sex Characteristics’

We have seen that different state responses to include intersex in status-based provisions use terms that intersex people do not identify with. The authors of the report suggest that ‘sex characteristics’ (kjønnskarakteristika) may be a more helpful term to use when drafting anti-discrimination, hate crime and hateful speech legislation in Norway to ensure it has broad coverage. Such a definition protects the congenital characteristics associated with intersex rather than framing intersex experience as an identity.<sup>96</sup> Moreover, it is crucial that intersex status is not defined as a form of transgender identity.

### 2.3.3 Recommendation 3: Flexible Gender Recognition Systems Rather Than Introduction of a Third Sex Category

We do not recommend the introduction of third sex categories or "X"-categories automatically for intersex people. Nevertheless, we acknowledge that other groups, for instance non-binary trans individuals, might wish this. Therefore, our recommendation is not designed to pass comment on the broader introduction of a third sex/gender marker. A flexible system for changing legal sex/gender on official documentation is recommended.

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<sup>96</sup> See also <http://insanhaklarimerkezi.bilgi.edu.tr/media/uploads/2015/07/31/Intersex.pdf> at page 46.

### 3 A NORWEGIAN ACTION PLAN

This section sets out an action plan of how our recommendations from section 2 can be implemented within Norway. This part therefore examines Norway's social, political and legal context to consider whether Norway's system is already meeting these broader recommendations and, if not, what specific changes can and should be made in order to offer substantive and holistic protection for intersex people. While Norwegian legislation does not contain any laws specifically aimed at intersex people, it is important to note that there is already a political consciousness in relation to redressing intersex issues. The government, for example, has issued an *action plan against discrimination on the basis of sexual orientation, gender identity and gender expressions 2017-2020*, which directly refers to intersex people. The action plan contains goals specifically aimed at intersex people as well as general goals aimed at LGBTI-people. The goals relating to intersex people are to:

- Develop research-based knowledge about the situation of intersex people in Norway and make recommendations for further research.
- Facilitate the creation of a meeting point for intersex people, at a health care centre for LGBT-people or initiated by an organization.
- Identify challenges and needs on the basis of research-based knowledge and the involvement of representatives.
- Examine issues concerning rights to new certificates/educational certificates and change of legal gender.

We therefore believe that the recommendations set out in section 2 will address a number of these goals.

Norway has provisions in place that offer a framework of basic protections and rights for all persons. Consequently, intersex people are protected by more general human rights provisions contained in the Constitution, in ratified international conventions as well as in patient's rights law or children's rights law. This section takes each recommendation from section two in turn and considers how Norway's approach currently fits within each of these and what further work is needed to ensure that Norway offers substantive and meaningful protections to intersex people.



### **3.1 Recommendation 1: Deferring Non-Therapeutic Medical Interventions Until the Individual Is Old Enough to Provide Informed Consent**

In Norway, two regional DSD-teams in Bergen and Oslo offer medical and surgical treatment to intersex people. When babies are born with an intersex variation, they are usually transferred within 1-2 days after birth to one of the DSD-teams.<sup>97</sup> The DSD-teams are specialized, and include personnel such as paediatric endocrinologists, paediatric and plastic surgeons, paediatric psychiatrists and nurses. The DSD-teams diagnose and treat children when their sex cannot be determined after birth, or later in life, if their sex or bodily characteristics does not develop normally. They treat different patient groups, for instance boys with hypospadias, girls with CAH, genetic mosaic conditions or different syndromes that affect the sex development.<sup>98</sup>

As aforementioned, Norway has no specific law or provision that regulates the medical and surgical treatment provided to intersex people. Their rights in relation to treatment are regulated through general patient rights laws, such as the Patients and Users Rights Act and the Specialized Health Care Services Act.<sup>99</sup>

An important principle within Norwegian health law is the autonomy of the patient. As a general rule, health care services can only be provided on the basis of the patient's consent. Children over 16 years have the legal competence to consent to treatment, but the age limit may be lowered or heightened depending on the situation, for instance the specific nature of the treatment.<sup>100</sup> As a main rule, parents consent to treatment when the child is below 16 years, but the child has the right to participate in the decisions according to their age and maturity.<sup>101</sup> The Patients and Users Rights Act was amended in 2017 to strengthen children's right to participation in health care decisions. For instance, the child's right to participation in health care decisions was lowered to 7 years old and children between 12 to 16 years old may consent to certain health care decisions without their parents.<sup>102</sup>

Another important principle is that health care services must be adequate, which means that health care must be necessary, include a certain level of quality and be based on scientific

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<sup>97</sup> Mari Rian Hanger, *Finner barnets egentlige kjønn*, *Dagens Medisin*, (22/2008).

<sup>98</sup> <https://forskningsprosjekter.ihelse.net/senter/rapport/FF-OUS-HB4/2016> accessed 15.9.2017.

<sup>99</sup> Their original titles are "Lov 2. juli 1999 nr. 63 om pasient- og brukerrettighet" and "Lov 2. juli 1999 nr. 61 om spesialisthelsetjenester."

<sup>100</sup> According to §§ 4-4 and 4-3 (1) b in the patient- and user rights act.

<sup>101</sup> According to § 4-4 (1) and (2) in the patient- and user rights act.

<sup>102</sup> Helse- og omsorgsdepartementet, Prop. 75 L (2016–2017) Endringer i pasient- og brukarrettslova, helsepersonellova m.m. (styrking av rettsstillinga til barn ved yting av helse- og omsorgstenester m.m.).

grounds. Health care staff have a legal duty to provide *adequate health care services*, and may face different sanctions or punishment if breached, cf. § 4 and chapter 11 in the Health Personnel Act (Helsepersonelloven). An important provision is also art. 6 in the ratified Biomedicine Convention from Council of Europe, which requires that treatment procedures that are carried out without the consent of the person involved must have a direct and immediate benefit.

While this general framework sets out some important rights for all people within Norway, there are some problematic areas in relation to deciding which treatments are classified as being ‘medically necessary’ treatments for intersex persons, as we will see. Moreover, there is a lack of research and follow up studies to intersex treatments which render such surgical procedures problematic under existing patient rights law and question whether the health care services provided are in fact ‘adequate.’

### 3.1.1 Current Health Care Provision for Intersex Persons in Norway: What Treatments Are Considered ‘Medically Necessary?’

For the global intersex community, the performance of non-therapeutic surgical interventions remains a key point for legal and political reforms.<sup>103</sup> However, the wish to prohibit these non-therapeutic surgeries needs to be balanced with access to therapeutic treatments. For example, Congenital Adrenal Hyperplasia results in a deficiency of the enzyme involved in the synthesis of cortisol, aldosterone, or both. This deficiency can result in salt-wasting which, if uncorrected, will lead to the death of the child. Clearly, in this example the salt-wasting is a medically necessary treatment. Consent, in this respect, does not conflict with the best interests of the child. Genital ambiguity, in contrast, is not immediate or life threatening. Surgery to ‘normalise’ the genitals would be unnecessary and should be deferred until the informed consent of the child can be confirmed.

Another contested treatment procedure, is the removal of gonads. Some intersex conditions have a heightened risk of cancer in the gonads, and they are therefore surgically removed. However, there is a diverse range of risk levels in relation to potentially cancerous gonads, and this is a topic where there is on-going research. For example, a representative from one of

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<sup>103</sup> The Intersex Society of North America (ISNA), International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) og Organisation Intersex International (OII) Advocates for informed choice.

the Norwegian DSD-team noted that the risk of cancer can be as high as 60% dependent on the intersex variation.<sup>104</sup> Other variations are as low as 2-3%.<sup>105</sup> Different medical teams are currently dealing with this 'risk' differently. Some parents are given the choice when their child does not have the sufficient age or maturity to decide for themselves. Some young people are given the choice when they are old enough to decide themselves (16 years old as a main rule). The assessment of the risk of cancer must be done carefully, as these procedures render intersex people reliant upon hormone therapy for the rest of their lives and may also make individuals sterile. Certainly, consideration is needed over how parents and affected individuals are introduced to the idea of cancer risk and supported to make an informed decision. This necessitates processes that involve on-going support. The UN has criticized procedures where gonads are removed, because they claim that the risk of cancer is not clear from the studies now available.<sup>106</sup> Distinguishing necessary treatment from deferrable treatment is therefore a key question in order to protect the best interests of intersex people.

Positively, the Norwegian DSD-teams have recently communicated a more cautious approach to the treatment of intersex people. In a letter to the Ministry of Health from 2016, the teams stated that they do not perform any treatment procedures on intersex children unless there is a so-called "medical-somatic indication".<sup>107</sup> Furthermore, they stated that they have not performed any surgeries based on so-called "psychosocial indications" (term used in the letter) on children between 2013 and 2015. This approach is communicated more clearly in recent works and reports than earlier, and can indicate a shift in the discourse as well as in the clinical practice.<sup>108</sup> This approach is also present in recent newspaper articles written by representatives from the DSD-teams.<sup>109</sup>

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<sup>104</sup> In Dagbladet 8.2.2017, available at <http://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>, accessed 28.4.2017.

<sup>105</sup> L Looijenga et al (2007) Tumor risk in disorders of sex development (DSD), *Clinical Endocrinology and Metabolism*, Volume 21, Issue 3, Pages 480–495.

<sup>106</sup> For example the Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (2015), OHCHR et.al., *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement* (WHO, 2014), the United Nations High Commissioner for Human Rights, *Discrimination and violence against individuals based on their sexual orientation and gender identity* (2015).

<sup>107</sup> This was stated in a joint letter by the DSD-teams in Oslo and Bergen to the Ministry of Health and Care services from September 2016. The letter was a response to a Ministry Inquiry where they, among other questions, asked how many surgeries that were carried out on children based on psychosocial indication versus medical-somatic indication between 2013 and 2015.

<sup>108</sup> For instance, Hanger, Mari Rian, «Finner barnets egentlige kjønn», *Dagens Medisin*, (22), 2008, <http://www.klikk.no/foreldre/baby/fodt-med-uklart-kjonn-2366629> accessed 15.9.2017, Bjerknes, R., «Forstyrrelser i den somatiske kjønnsutviklingen (4): Utredning av nyfødte med uklare kjønnskarakteristika», *Pediatrisk Endokrinologi*, 22 (1), 2008, Diseth, Trond H., «Children born with ambiguous genitalia», *Tidsskrift for den Norske lægeforening : tidsskrift for praktisk medicin, ny række*, 128 (5), 2008, 576.

<sup>109</sup> <https://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633> accessed 15.9.2017.

While we welcome this shift, a concern is that this approach is not sufficiently reflected in current medical and ethical guidelines within Norway (and thus there is a risk that practitioners do not comply with this approach). Additionally, the definition of ‘psychosocial’ is not clear. In the aforementioned letter, the DSD-teams defined clitoral reductive surgeries to virilised CAH-girls as the only surgical procedure that has a psychosocial indication.<sup>110</sup> Other procedures performed by the teams such as hypospadias-correction and surgical procedures on the vagina are not listed as psychosocial. However, in human rights literature, hypospadias-correction with cosmetic purposes and to enable boys to urinate standing and vaginal surgeries with the aim to create possibilities for penile penetration, are categorized as procedures that are not medically necessary<sup>111</sup> in terms of functionality. The letter from the DSD-teams indicates that all of the treatments were medically necessary. We stress the need for clarifications to ensure that where procedures can be deferred they are not being performed, so that the intersex individual can give informed consent. This may mean deferring them until the child is able to understand the information presented to them.

Furthermore, the DSD-teams stated in the letter that they only remove gonads when there is a risk of cancer. This implies that the removal of gonads are not performed to assign or correct the “ambiguous” sex characteristics of intersex people, but to prevent cancer. As previously mentioned, commentators such as the UN question the assessment of the risk of cancer, and claim that the surgeries are performed without adequate proof of a real and immediate risk.<sup>112</sup>

Against this background, there is a real need to revisit the process of removing gonads on the basis of the risk of cancer. The timing of the surgery must be carefully examined, and the child’s right to self-determination concerning bodily interventions should be respected to the highest possible extent. Specific and detailed recommendations on treatment procedures are necessary to work in conjunction with legislation, and we recommend that relevant guidelines clarifies the term “medically unnecessary” to refer to procedures that can be deferred. Moreover, careful consideration of how ‘risk’ is introduced to individuals and their families

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<sup>110</sup> *Ibid.* in the letter page 4.

<sup>111</sup> For example Erin Lloyd, *From hospital to the courtroom: a statutory proposal for recognizing and protecting the legal rights of intersex*, Cardozo Journal of Law and Gender, (12/2005–2006) on p. 182 and 161, the Council of Europe Commissioner for Human Rights, *Human rights and intersex people* (2015) p. 21, Samantha S. Uslan, *What parents don't know: informed consent, marriage, and genital-normalizing surgery on intersex children*, Indiana Law Journal, 85 (1), 2010, 301-323, Jameson Garland, *On Science, Law, and Medicine: The case of gender- “normalizing” interventions on children who are diagnosed as different in sex development*, (Uppsala University, 2016).

<sup>112</sup> OHCHR et.al., *Eliminating forced, coercive and otherwise involuntary sterilization: an interagency statement* (WHO, 2014).

is needed, coupled with on-going support for individuals and parents to ensure that individuals are making fully informed decisions.

The DSD-teams' practice has also been debated in the national newspaper *Dagbladet*. After the Belgian model Hanne Gaby Odiele revealed her intersex condition in January 2017, several newspaper articles have been published that are critical of the Norwegian medical practice.<sup>113</sup> Leaders from relevant NGOs wrote a feature article in January, claiming that the Norwegian treatment practice breached the United Nations Convention on the Rights of the Child.<sup>114</sup> Representatives from the two DSD-teams wrote a response in the same newspaper in February 2017, and clarified that Odiele's case is not representative of today's treatment practice in Norway.<sup>115</sup> Women with CAIS, like Odiele, participate in treatment decisions on whether they want to remove the sex gonads or not. In this piece, the DSD-teams emphasized the lack of scientific knowledge around optimal health care decisions, for instance estimating the risk of cancer if the gonads are not surgically removed. As these intersex conditions are rare, it is difficult to obtain studies that are representative.

In the DSD-teams' response, they wrote that today, there is no pressure to "normalize" the body and that it is important to acknowledge the different bodily variations. They described that the treatment practice has changed, and that they now have a different approach when it comes to assessing the best interests of the child. It is very positive that the DSD-teams contribute in these debates in order to clarify their practices. We observe that the language of the DSD-teams in the article is different from what we have seen in previous work and descriptions of the health care.<sup>116</sup> When debating intersex in a national newspaper, it is positive that the teams use a non-medicalized language, for instance they use the term "intersex" and "sex variations" instead of "disorder" or "diagnosis." We welcome this new approach, and recommend that it is reflected in their medical and ethical guidelines to ensure that this is embedded in practice. Moreover, it is clear that distinguishing medically necessary from medically unnecessary grounds (i.e. deferrable treatments) needs to be state-led to ensure compliance from medical practitioners and also to ensure that medical interventions

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<sup>113</sup> Dagbladet 31.1.2017 (<http://www.dagbladet.no/kultur/norge-bryter-med-fns-barnekonvensjon/66922729>), Dagbladet 29.1.2017 (<http://www.dagbladet.no/kjendis/hanne-28-ble-utsatt-for-operasjoner-som-ikke-var-medisinsk-nodvendig---det-ble-et-traume-pa-grunn-av-det-de-gjorde/66908547>).

<sup>114</sup> Dagbladet 31.1.2017 (<http://www.dagbladet.no/kultur/norge-bryter-med-fns-barnekonvensjon/66922729>)

<sup>115</sup> Dagbladet 8.2.2017 (<http://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>).

<sup>116</sup> For instance, Hanger, Mari Rian, «Finner barnets egentlige kjønn», *Dagens Medisin*, (22), 2008, <http://www.klikk.no/foreldre/baby/fodt-med-uklart-kjonn-2366629> accessed 15.9.2017, Bjerknes, R., «Forstyrrelser i den somatiske kjønnsutviklingen (4): Utredning av nyfødte med uklare kjønnskarakteristika», *Pediatrisk Endokrinologi*, 22 (1), 2008, Diseth, Trond H., «Children born with ambiguous genitalia», *Tidsskrift for den Norske lægeforening : tidsskrift for praktisk medicin, ny række*, 128 (5), 2008, 576.

happening before a child is able to give informed consent are not based on psychosocial grounds (and thus deferrable).

### 3.1.2 Implementing our First Recommendation in Norway: Action Points

To ensure the best protections for intersex persons with regard to ending non-therapeutic surgeries on intersex children, our action plan for Norway is that treatment procedures that can be deferred are not performed until the child can consent. This part discusses whether this recommendation best can be implemented by introducing a legal prohibition or amending medical standards, or both.

#### 3.1.2.1 *Deferring Non-Therapeutic Medical Interventions on Children: Redefining the Term ‘Medically Unnecessary’*

Our first general recommendation refers to the categorization of ‘medically unnecessary’ intersex treatments within Norway. It is important to underline that labelling a treatment as medical unnecessary does not mean that it is illegitimate or illegal. Many procedures offered by health personnel that are not strictly medically necessary, are still perceived as acceptable and legal health care services, for instance surgeries on cleft palate, ear-pinning or reconstructive surgeries with cosmetic purposes. However, genital surgeries may conflict with the best interests of the child particularly where the surgical and medical ‘correction’ of the child proves to be incorrect, or where the surgery causes a lack of sexual function, or where the child is sterilized. For these reasons, non-therapeutic interventions on intersex children must be deferred until they can participate in the decision.<sup>117</sup> Thus, such treatments should not take place on children without their consent.

Perhaps a better term than "non-therapeutic" or “medically unnecessary” is the Maltese provision on *treatment procedures that can be deferred*, because it focuses on the *timing* of the treatment in question without labelling it as unnecessary or illegitimate. Intersex people with the capacity to consent might have legitimate wishes to perform these procedures, and it can be viewed as stigmatizing to label them as unnecessary. The overall aim must be to protect children against irreversible and potentially harmful treatment that can be deferred

until they can decide for themselves. This is a matter of choice: only intersex individuals should be able to consent to such ‘normalizing’ measures when they have reached an age with sufficient capacity to do so. Given that there are discrepancies over the term ‘unnecessary’, clear guidelines informed by research and the intersex community are needed. In order to carefully map out recommendations for updated guidelines in this difficult field, expertise in medicine, ethics and law as well as the intersex community are needed.

An important question is if there should be a *legal prohibition* on treatment procedures that can be deferred, as in Malta. Almost all of the legal literature in this area recommends that intersex children should make their own decisions concerning medical and surgical treatment.<sup>118</sup> Nevertheless, states have been hesitant to initiate concrete actions to answer these calls. Despite clear recommendations from different independent state bodies like ethics councils and ombudspersons, as well as international human rights organizations like the UN and the Council of Europe, the implementation of these recommendations has been poor. As described in the comparative section, Malta is the only country that has prohibited treatment decisions that can be deferred. In a Norwegian context, the question is how this recommendation can be best implemented, considering the particular needs, legal system and different ongoing legal processes and policies.

There are different ways to change medical practices to ascertain that such recommendations are followed. As mentioned, Chile for example, has attempted to regulate the treatment through medical guidelines as an interim measure. In a recent study by Garland and Travis (2018) however, intersex respondents overwhelmingly reported the desire for these changes to come from law rather than medicine. They believed that a legislative approach would lead to more significant changes and tighter regulation of this area.

In the medical field, the Norwegian legal landscape consists of broad and generally formulated health laws. Despite some specialized health care laws, most of the norms concerning optimal health care practices are laid down through guidelines.<sup>119</sup> Broad legal principles such as the duty to provide adequate health care services in the Act on Health Care

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<sup>118</sup> M Fox, & M Thomson (2006) ‘Cutting it: Surgical Interventions and the Sexing of Children’, 12 *Cardozo Journal of Law and Gender* 81-97. E Grabham, (2012) ‘Bodily Integrity and the Surgical Management of Intersex’ 18 *Body and Society* 1-26. P-L Chau & J Herring (2002) ‘Defining, Assigning and Designing Sex’ 16 *International Journal of Law, Policy and the Family* 327-367. F Ammaturo (2016) ‘Intersexuality and the ‘Right to Bodily Integrity’; Critical Reflections on Female Genital Cutting, Circumcision, and Intersex ‘Normalizing Surgeries’ in Europe’ 25 *Social and Legal Studies*, 591-610.

<sup>119</sup> Often made by the Directorate of Health or by the health care teams themselves.

Personnel are beneficial to make room for flexible case-by-case assessments that are necessary for providing the best treatment for every patient. A law or a provision specifically targeting the treatment of intersex individuals may therefore be inconsistent with the Norwegian legal system in the health care field. In addition, it is problematic to introduce a legal prohibition and sanctions that only applies to relatively small clinical teams.

The advantage of guidelines is that relevant health care actors often are involved in the work, which increases the likelihood that the guidelines are used in clinical practice. Furthermore, the format of the guidelines allows for a more thorough explanation than in legal texts. In this case, the decision-making processes are complex because the treatment procedures and the various intersex diagnoses are very different.

Such guidelines can be used in conjunction with legal reform, for instance a legal prohibition on unnecessary treatment or treatment that can be deferred. The advantage is that intersex children will have a clearer legal protection, and may pursue potential breaches of the provision in the legal system. It also sends out a very clear message that intersex children's autonomy and bodily integrity must be respected. A prohibition would also answer the clear demand from UN and other actors urging states to stop unnecessary treatment on intersex children. We would welcome new guidelines to come from within the DSD-teams/medical profession after interaction and dialogue with intersex groups. We understand that it is a challenge to include intersex people when there is no organization that uniquely represents this group. The initiatives envisaged in the action plan, for instance to support the establishment of a meeting point for intersex people, are important in order to facilitate a platform where intersex people can formulate common needs and interests.

Finally, the DSD-teams have communicated a more cautious approach than earlier, which diminishes the need for a legal prohibition. However, in its current form there is a lack of oversight as to how this is implemented, monitored, and enforced. A long term solution is to add an even broader provision that generally prohibits procedures that can be deferred until the child can participate in the decision. The provision should apply to different kinds of procedures performed on children, for instance alternative treatment or other cosmetic procedures, not only treatment decisions in relation to intersex.



In the short term, updated medical guidelines and ethical examination of the treatment practices are recommended actions (See 3.1.2.2 below).

### *3.1.2.2 Updating Medical Guidelines*

As aforementioned, in the short term, medical guidelines should be updated and the role of ethics in decisions relating to treatment should be strengthened. Norway already has a duty on health personnel to provide adequate health care services, which also includes duties around good quality and documented positive effect. In combination with clear guidelines that indicate optimal practice in relation to the duty to provide adequate health care services, intersex people could have a sufficient protection, as potential breaches could be met by administrative sanctions.

To do this, new or updated treatment guidelines should be introduced in Norway. These new protocols should be created by a team of experts in ethics, medicine and law as well as experts with sound research-based knowledge and psycho-social expertise, and include intersex people in the drafting process, if possible. These guidelines will seek to clarify which procedures can be deferred until the person concerned can give informed consent. We would also recommend the introduction of a working party composed of intersex people, medical practitioners and human rights experts to evaluate whether current medical treatment protocols are in line with human rights standards and medical best practices.<sup>120</sup>

A similar approach as the national ethics council (see section 3.1.2.3) could be beneficial. However, Norway does not have an equivalent national ethics council.<sup>121</sup> Norway has ethical committees, but they only operate on the clinical level.<sup>122</sup> In terms of evaluating the treatment procedures, this may be beneficial as it can increase the medical and ethical quality of healthcare services. At the same time, we fear that clinical committees, as primarily an internal component of the hospital, do not have the capacity to introduce the sweeping reforms that we recommend.

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<sup>120</sup> See GIGESC s 16.

<sup>121</sup> A national body with medical-ethical expertise is The Biotechnology Advisory Board (Bioteknologirådet), but as their mandate is limited to biotechnology, it is more likely that they address related questions such as fertility treatment etc. (<http://www.med.uio.no/helsam/english/research/projects/clinical-ethics-committees-in-hospitals/index.html> 25.1.2017). We also encourage other relevant state bodies to engage, for instance The Parliamentary Ombudsman or the Ombudsman for Children.

<sup>122</sup> See <https://www.etikkom.no/FBIB/Praktisk/Forskningsetiske-enheter/Kliniske-etikkomiteer/>, accessible 27.4.2017.

### 3.1.2.3 Strengthening the Role of Ethics in Treatment Decisions

While non-therapeutic treatments should be deferred until the individual is old enough to give informed consent, there may be exceptional circumstances whereby irreversible or invasive surgical treatment is required without the informed consent of the child. In these exceptional circumstances, the role of ethics in the decision-making process concerning treatment to intersex people is very important, particularly in treatment decisions without a clear medical indication. In these circumstances the aforementioned ethics committees would offer guidance as to whether the medical interventions were deferrable. An illustration of the importance of ethics, is the number of ethical examinations of the treatment practices undertaken by public bodies, for instance in Australia, Germany, Sweden, Switzerland and Finland.<sup>123</sup>

A general recommendation for Norway is an enhanced and more careful decision making process in intersex cases that require difficult ethical considerations. Malta offers some useful insight here. Section 14(5) *Gender Identity, Gender Expression and Sex Characteristics Act* 2015 provides that in such instances, an interdisciplinary panel appointed by the Minister is always involved and is responsible for:

- (a) ensur[ing] that the best interests of the child as expressed in the Convention on the Rights of the Child be the paramount consideration; and
- (b) giv[ing] weight to the views of the minor having regard to the minor's age and maturity.

We would suggest similar points should be considered by an ethics committee within Norway.

In terms of composition, clinical ethics committees, connected to the specialized health care facilities, could be involved in such cases. Today these committees are involved on a

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<sup>123</sup> The German Ethics Council, *Opinion: Intersexuality*, (Deutscher Ethikrat 2013), Swiss National Advisory Commission on Biomedical Ethics, *On the management of difference of sex development. Ethical issues relating to "intersexuality"* (Opinion no. 20/2012). The Senate Community Affairs Committee Secretariat in Australia, *Involuntary or coerced sterilisation of intersex people in Australia*, Australia 2013. Socialstyrelsen, *Vård och behandling av personer med intersexuella tillstånd Kartläggning av det tidiga omhändertagandet* (2017), available at <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20474/2017-1-24.pdf> accessible 27.4.2017, Finnish Advisory Board on Social Welfare and Health Care Ethics (ETENE), *CARE AND TREATMENT OF INTERSEX CHILDREN* (2016), available at <http://etene.fi/documents/1429646/1561478/2016+POSITION+STATEMENT+intersex/77dc4b30-2a6d-4811-aa99-c30032f400b0> accessible 27.4.2017. The Icelandic Ombudsman of Children have written an opinion, see <http://www.ilga-europe.org/sites/default/files/2016/iceland.pdf>, accessed 27.4.2017.

voluntary basis.<sup>124</sup> To ensure sufficient protection for the patient, particularly children, involvement of the committee should be routine and could be laid down in statute and medical guidelines. Involvement of a third party should also ensure more neutrality in the decision-making process. Other bodies could also be used to approve different treatment procedures. In Sweden, it is the National Board of Health and Welfare (Socialstyrelsen) that approves sex reassignment procedures in relation to the act concerning gender recognition. The equivalent body in Norway is the Directorate of Health (Helsedirektoratet). Another alternative is to include personnel with ethical expertise internally in the DSD-teams.

### 3.1.2.4 Informed Consent: Ensuring Access to Information

Where exceptional circumstances<sup>125</sup> require parents to consent to treatment on their child's behalf, it is important that they receive appropriate information. However, health care personnel have been criticized for presenting the birth of an intersex child as a "medical emergency" to the parents (not related to Norway). Sociologist Morgan Holmes has argued that medical literature and guidelines contain a discourse of emergency that may encourage parents to make hasty decisions concerning treatment.<sup>126</sup> Moreover, research has indicated that the way health personnel inform parents about intersex, is crucial for how they understand their options around treatment decisions. A study from 2013 illustrates this.<sup>127</sup> 66 % of the participants (27 of 41) that saw a medicalized information video preferred early surgery, while only 23 % (11 of 48) that saw the non-medicalized information video wanted early surgery. Consequently, research has indicated that parents' decisions are affected by what kind of information they get. This also highlights the need for non-medics to be involved in the decision making process, such as people with psycho-social expertise.

Current Norwegian medical guidelines indicate that an intersex baby should be transferred to a DSD-team promptly after birth, preferably within 1-2 days<sup>128</sup> so that the child can be quickly examined to determine whether they have any life-threatening conditions. This can

<sup>124</sup> See <http://www.med.uio.no/helsam/tjenester/kunnskap/etikk-helsetjenesten/spesialisthelsetjenesten/index.html>, accessed 2.2.2017.

<sup>125</sup> Note that exceptional circumstances would not include non-therapeutic interventions (see above).

<sup>126</sup> Morgan Holmes, *Distracted Attention: Intersexuality and Human Rights Protections*, *Cardozo Journal of Law and Gender*, (1/2005), at 127-134, Tove Lundberg, Anders Lindström, Katrina Roen and Peter Hegarty, *From Knowing Nothing to Knowing What, How and Now: Parents' Experiences of Caring for their Children With Congenital Adrenal Hyperplasia*, *Journal of Pediatric Psychology*, 2016, 1–10.

<sup>127</sup> Streuli, Jürg C., Vayena, Effy, Cavicchia-balmer, Yvonne og Huber, Johannes, *Shaping Parents: Impact of Contrasting Professional Counseling on Parents' Decision Making for Children with Disorders of Sex Development*, *Journal of Sexual Medicine*, 10 (8), 2013, at 1956.

<sup>128</sup> Trond H. Diseth, *Children born with ambiguous genitalia*, *Tidsskrift for den norske legeforening* (5/2008)

be an emotional time for the parents, and it is crucial that they get correct and objective information. In the February 2017 feature article mentioned above, the DSD-teams communicated a perspective of intersex as a bodily variation that does not have to be "normalized".<sup>129</sup> It is very important that this information is carried through into their dealings with parents in order to ensure that they are fully supported. This can be achieved in a number of ways:

- Clear guidance to health personnel can contribute to ensuring that parents are unable to choose 'normalizing' surgeries for their child.
- Where exceptional circumstances exist,<sup>130</sup> health personnel must inform parents in a balanced way about the risks and advantages concerning different treatment options so that they can make informed decisions (which would also include information on the child's best interests and why surgeries should be deferred until the child can decide for itself).
- An ethics panel (see section 3.1.2.3) will also aid parents when making such fundamental decisions relating to treatment.

### *3.1.2.5 The Need for More Research*

In the February 2017 feature article, the DSD-teams stressed that more research is needed.<sup>131</sup> We would counter this position by highlighting that there are no qualitative studies that highlight the benefits of non-therapeutic surgical intervention. As a result, medical and surgical treatment that can be deferred should not take place on children until they are able to give informed consent. An increase in patient-led research-based knowledge is important to determining the best outcomes for intersex people. Intersex people should be included in the research concerning different groups living conditions, challenges and needs. There is a difference, however, between research 'with' the intersex community and research 'on' the intersex community. We support the aim for engaging with intersex people if possible, to assess their needs.

The two Norwegian DSD-teams have applied for the establishment of a so called "quality register", which will enable them to systematically gather information concerning effects of

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<sup>129</sup> Dagbladet 8.2.2017 (available at <http://www.dagbladet.no/kultur/behandlingen-av-modellen-hanne-er-ikke-representativ/67014633>, accessed 27.4.2017).

<sup>130</sup> Malta uses this term 'exceptional circumstances'.

<sup>131</sup> Ibid.

the treatment.

We also recommend cross-country initiatives, such as research projects and registers that collect data from different countries (for instance the Nordic countries), in order to allow greater oversight of the quality and effects of the treatment practices.

### **3.2 Recommendation 2: Meaningful Incorporation of Intersex within Anti-Discrimination, Hate Crime and Hateful Speech Legislation by Including References to ‘Sex Characteristics’**

This section will first consider the current provisions in Norway relating to anti-discrimination law and second consider Norway’s hate crime and hateful speech legislation. While revisions to anti-discrimination and hate crime/hateful speech provisions are important, this needs to be part of a holistic reform.

#### **3.2.1 Current Anti-Discrimination Provisions for Intersex Persons in Norway**

The Norwegian Equality and Anti-discrimination Ombud has indicated that discrimination against intersex people does exist.<sup>132</sup> Even though anti-discrimination legislation is not among the most prioritized issues for intersex people,<sup>133</sup> it is beneficial to have in place legislation that can offer protection in cases of discrimination against intersex people. A new common anti-discrimination law was adopted in Norway summer 2017, and includes the four previous anti-discrimination laws.<sup>134</sup> The law entered into force 1.1.2018. Among these laws it is the 2013 act prohibiting discrimination on the basis of sexual orientation, gender identity and gender expression, which was the most relevant law for intersex persons. This Act provided intersex persons with a general protection against direct and indirect discrimination.<sup>135</sup> The new law includes the same discrimination grounds as the 2013 act, and

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<sup>132</sup> So far, there are no cases of discrimination based on sex characteristics registered at the Norwegian equality and anti-discrimination ombudsman (Likestillings- og diskrimineringsombudet). Nevertheless, they have registered an inquiry from an intersex person reporting on bullying at his workplace because of atypical sex characteristics.

<sup>133</sup> According to a study carried out by Garland and Travis (2018), The Intersex Society of North America (ISNA), International Lesbian, Gay, Bisexual, Trans and Intersex Association (ILGA) og Organisation Intersex International (OII) Advocates for informed choice.

<sup>134</sup> The law was decided 16.6.2017, cf. Lovvedtak 118 (2016-2017) Lov om likestilling og forbud mot diskriminering (likestillings- og diskrimineringsloven). The law replaces the four existing discrimination laws into one law with six grounds (two of these being new additions).

<sup>135</sup> The original title is "Lov 21. Juni 2013 nr. 50 mot diskriminering på grunn av seksuell orientering, kjønnsidentitet og kjønnsuttrykk".

will therefore principally provide the same protection as before. The aim is to ensure a more efficient legal protection against discrimination, and to ensure equality between the different grounds of discrimination. In the following, the 2013 act will be examined, but the comments are also relevant for the new common discrimination law.

While ‘intersex’ is not explicitly mentioned in the law, according to the preparatory work to the law, intersex people are included in the formulation “gender expressions” (kjønnsuttrykk). It therefore follows directly from the preparatory work that intersex people are protected by the law. This is also confirmed in the preparatory work to the new discrimination law.<sup>136</sup>

It is positive that the law has attempted to stretch its anti-discrimination legislation to incorporate “intersex”.<sup>137</sup> Nevertheless, the legal term “gender expression” has some weaknesses in the context of intersex as it is less obvious that it also encompasses *physical* sex characteristics (kjønnskarakteristika) (see also our discussions in section 2.1.3.B). The ordinary meaning of “gender expression” is how one performs gender, and not necessarily bodily characteristics. Thus, in practice it may be difficult for intersex persons to access the protections afforded by this piece of legislation. In one section of the preparatory work, gender expression is defined as the way in which a person intentionally or unintentionally expresses their gender identity through, for instance, their voice, clothing, gestures, make up, etc. and how other people perceive a person’s gender identity.<sup>138</sup> This definition is more relevant in cases of trans issues and since it does not mention physical or bodily sex characteristics, there is a risk that the term in the law does not offer intersex people sufficient protection in practice, even though it follows from the preparatory work that intersex people are included.

There is also an act prohibiting discrimination on the basis of disability (Lov om forbud mot diskriminering på grunn av nedsatt funksjonsevne), but there are questions as to how far intersex people can use this legislation to tackle discriminatory practices. Julie Greenberg examines the question of whether medical procedures towards intersex people constitute

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<sup>136</sup> Barne- og likestillingsdepartementet, Prop.81 L (2016-2017), Lov om likestilling og forbud mot diskriminering (likestillings- og diskrimineringsloven) p. 313.

<sup>137</sup> Lisdonk (2014).

<sup>138</sup> . Barne- og likestillingsdepartementet. Prop. 88 L (2012–2013) Chapter 16.1.2. The original text «Med *kjønnsuttrykk* menes hvordan kjønnsidentiteten bevisst eller ubevisst uttrykkes eller oppfattes av andre, for eksempel med stemme, klær, kroppsspråk, sminke eller frisyre».

disability discrimination.<sup>139</sup> Some intersex people have a condition that will qualify as a disability in itself, for instance DSD-diagnosis that impairs the endocrine and bladder function or results in infertility. However, most intersex variations do not have a disabling effect. It is possible that treatment procedures might lead to impairments that can qualify as a disability. The act also protects people against discrimination based on a *perceived* disability. Nevertheless, many intersex people do not wish to use the disability legislation, because of the stigma associated with the term and the medicalization which it may produce.<sup>140</sup> They fear that by labelling the intersex variations as disabilities, the unnecessary treatment procedures will only increase. Greenberg concludes that although most intersex people do not identify as disabled, the discrimination legislation could function as an efficient tool to tackle medical unnecessary treatments.

Overall, anti-discrimination law in its current format in Norway does not offer intersex persons sufficient protection by only referring to gender expression (kjønnsuttrykk), and is therefore in need of revision to include physical sex characteristics.

### 3.2.2 Implementing Our Second Recommendation in Norway: Action Point 1 – Including an Intersex-Specific Category Within Norway's Anti-Discrimination Law

On this background, we believe that the current discrimination legislation does not offer intersex people sufficient legal protection and thus is in need of reform. As aforementioned in section 2.2, both Malta and Australia offer positive ways of incorporating intersex persons into anti-discrimination law. We would recommend that the anti-discrimination legislation in Norway be amended so that it explicitly mentions the term 'sex characteristics' (kjønnskarakteristika) or 'bodily variations' (kjønnsvariasjoner). This is preferential to the term 'intersex' as the term 'sex characteristics' has broader coverage. Such a definition protects the congenital characteristics associated with intersex rather than framing intersex experience as an identity.<sup>141</sup> Moreover, it is crucial that intersex status is not defined as a form of transgender identity and thus should not be cast as a form of gender expression.

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<sup>139</sup> Julie A. Greenberg, *Health Care Issues Affecting People with an Intersex Condition or DSD: Sex or Disability Discrimination?*, 45 Loy. L.A. L. Rev. 849 (2012).

Available at: <http://digitalcommons.lmu.edu/llr/vol45/iss3/5>.

<sup>140</sup> Julie A. Greenberg, *Health Care Issues Affecting People with an Intersex Condition or DSD: Sex or Disability Discrimination?*, 45 Loy. L.A. L. Rev. 849 (2012) p. 902.

In its current form, we would suggest that the appropriate place for amendment would be to alter the new discrimination act to include the term ‘sex characteristics’ (kjønnskarakteristika) or ‘bodily variations’ (kjønnsvariasjoner) to better incorporate intersex people. Using disability discrimination is not appropriate given the stigma and medicalization associated with it; individuals may be deterred from using such legislation if they do not want to engage with the medical profession.

Before deciding the new common discrimination law, there were a number of debates in Norway on whether it was beneficial to combine the different discrimination laws into one holistic piece of discrimination legislation, or whether Norway should keep several laws in different fields.<sup>142</sup> It is unclear whether one discrimination law would automatically improve the position of intersex persons as the discrimination grounds applicable to intersex people might become less visible. A positive consequence of imitating one discrimination law, is that it might have stronger outreach than the current discrimination law that applies to sexual orientation, gender identity and gender expression, which mostly applies to LGBT-cases. As many intersex people feel little connection to LGBT-people, a more general law that encompasses several discrimination grounds on an equal basis, could be beneficial; and may facilitate greater coalition building.

### 3.2.3 Current Hate Crime and Hateful Speech Provisions for Intersex Persons in Norway

In Norway, hate crime is not a legal term, but hateful speech is explicitly regulated in the criminal code. However, some provisions forbid actions that in practice constitute hate crime. The criminal code § 185 forbids discrimination or hate speech motivated by skin colour, national or ethnic origin, religion or life stance, homosexual orientation or disability. Furthermore, § 186 in the criminal code regulates discriminatory actions, by forbidding a person or body to deny a person goods or services motivated by the same reasons as mentioned in § 185. In addition, hateful motivated actions can increase prison sentences cf. § 77 letter e. The absence of intersex-specific provisions in the criminal code, such as the term sex characteristics, means that intersex people do not have sufficient legal protection against hate speech and hate crime. The invisibility of intersex people in Norwegian society is concerning, and hate speech and hate crime towards intersex people makes it even harder for intersex

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<sup>142</sup> Barne-, likestillings- og inkluderingsdepartementet, Høring - forslag til felles likestillings- og diskrimineringslov (2015), available at <https://www.regjeringen.no/contentassets/5342e1dd1467426a98d4b02b7a4a79ca/horingsnotat.pdf>, accessed 28.4.2017.



people to be open about themselves, and to express their needs and interests.<sup>143</sup> It is therefore important that intersex people have an adequate legal protection against hate speech and hate crime.

### 3.2.4 Implementing Our Second Recommendation in Norway: Action Point 2 – Including an Intersex-Specific Category Within Norway’s Hate Crime and Hateful Speech Legislation

While hate crime provisions in Norway are currently weak and in need of reform, there are ongoing legal and political processes that aim to strengthen the protection of LGBTI-people against hate crime and hateful speech. Most notably, the regulation of criminal discrimination is currently being revised. A report commissioned by the Ministry of Children and Equality from 2016 recommended that sex, gender identity and gender expression should be added within the criminal code as illegal grounds of discrimination.<sup>144</sup> Currently sex, gender identity and gender expression are rarely mentioned;<sup>145</sup> and the only clear reference to sexual minorities is the term *homosexual orientation*. We would also recommend adding sex characteristics (kjønnskarakteristika) to this list to protect intersex people (see section 2.2 for our justification for preferring the term ‘sex characteristics’ over ‘intersex’ within legislation).

Following on from this 2016 report, the Ministry of Children and Equality and the Ministry of Justice and Public Security have a common measure regarding hate crime legislation in the a 2017-2020 action plan against discrimination on the basis of sexual orientation, gender identity and gender expressions. Here the Ministries will examine the provisions relating to hate crime in the criminal code with the aim to find out how gender identity and gender expressions can be protected. Additionally, the Government has issued a strategy against hate speech, which also refers to gender expression and thus (in its current definition) will implicitly include intersex.<sup>146</sup> We consider this work important to increase the legal protection for people that challenge perceptions of sex and gender, including intersex people. We recommend that intersex issues also be addressed in the examination, and that any law

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<sup>143</sup> Lisdonk (2014) p. 54.

<sup>144</sup> Kjetil Mujezinović Larsen *Utredning om det strafferettslige diskrimineringsvernet* (2016). The Ministry of Children and Equality appointed Larsen from the Norwegian Centre for Human Rights to examine the criminal prohibition of discrimination. Available at <https://www.regjeringen.no/no/dokumenter/utredning-om-det-strafferettslige-diskrimineringsvernet/id2520561/>, accessed 31.1.2016.

<sup>145</sup> Larsen (2016) at 66.

<sup>146</sup> Barne- og likestillingsdepartementet, Regjeringens strategi mot hatefulle ytringer 2016 – 2020, available at [https://www.regjeringen.no/contentassets/72293ca5195642249029bf6905ff08be/hatefulleytringer\\_uu.pdf](https://www.regjeringen.no/contentassets/72293ca5195642249029bf6905ff08be/hatefulleytringer_uu.pdf), accessed 1.5.2017.

proposal include terms like sex characteristics, that will include intersex people. We would not recommend the use of ‘gender expression’ to include intersex persons into legislative reform as discussed above (see section 3.5.1).

As hate crime is not yet a legal term, an important question is how this term should be legally defined. The police in Oslo have formulated hate crime as "illegal actions that partly or fully are motivated by negative attitudes towards ethnicity, religion, homosexual orientation and disabilities".<sup>147</sup> We believe that this definition does not sufficiently include intersex people, and should contain a reference to sex characteristics. In the same report, the police in Oslo stated that it is preferable that terms such as “gender identity” or “gender expression” are explicitly mentioned in the criminal law, and mention trans people as a target group.<sup>148</sup> A report by the Equality and Anti-Discrimination Ombud from 2015 contains recommendations in relation to the definition of both hate crime and hate speech.<sup>149</sup> The definitions are not legal, as they both encompass legal and illegal actions. Nevertheless, both definitions contain reference to gender expression.<sup>150</sup> It is positive that the proposed definitions explicitly mention gender expression, but sex characteristics would be more suitable to protecting intersex people as, once again, the use ‘gender expression’ is not an ideal legal term to refer to intersex persons (see section 3.5.1 above).

### **3.3 Recommendation 3: Flexible Gender Registration Systems Rather Than an Introduction of a Third Sex Category to Recognise ‘Intersex’**

#### **3.3.1 Current Gender Registration Systems in Norway**

Norway recognizes two official sex categories: male and female. Official registers and documents like the National Register, Birth Register and passports contain male and female sex markers. Furthermore, health personnel have a duty to report the sex of a newborn baby

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<sup>147</sup> Oslo Politidistrikt, *Hatkriminalitet. Anmeldt hatkriminalitet 2015* (2016) at. 3 Translation by the authors. See also Oslo Politidistrikt, *Hatkrim. Rettslige og praktiske spørsmål*, Rett på gata (2015).

<sup>148</sup> Oslo Politidistrikt (2016) at 8.

<sup>149</sup> Likestillings- og diskrimineringsombudet, *Hatytringer og hatkriminalitet* (2015), available at <http://www.ldo.no/nyheter-og-fag/brosjyrar-og-publikasjoner/rapporter/hatytringer-og-hatkriminalitet/>, accessed 1.5.2017.

<sup>150</sup> Original text: ”Hatytringer er nedverdiggende, truende, trakasserende eller stigmatiserende ytringer som rammer individets eller en gruppes verdighet, anseelse og status i samfunnet ved hjelp av språklige og visuelle virkemidler som fremmer negative følelser, holdninger og oppfatninger basert på kjennetegn, som for eksempel etnisitet, religion, kjønn, nedsatt funksjonsevne, seksuell orientering, kjønnsuttrykk, kjønnsidentitet og alder” and ”Hatkriminalitet er straffbare handlinger som helt eller delvis er motivert av negative holdninger til en personens faktiske eller oppfattede etnisitet, religion, seksuelle orientering, kjønnsuttrykk og/eller nedsatte funksjonsevne” at page 5-8.

to the Birth Register within a month after they leave the clinic.<sup>151</sup> Whilst there is some flexibility in notifying the birth register about the sex, the register itself does not have any real alternatives to male or female. It is currently not possible to choose a third marker or to refrain from using a gendered marker/social security number. Consequently, institutions such as law place intersex persons into categories of male and female before it is possible to ascertain the child's gender identity. Although most intersex people define themselves as male or female, flexibility needs to be built into the system in order to rectify any mistakes that medical professionals and families may have made in assessing the child's sex as the child grows older and is better able to articulate their gender identity. The recent law on gender recognition addresses these situations by giving parents of DSD-children possibilities to change their legal gender at any time. Nevertheless, we believe that the birth register in itself can be more flexible by allowing for delayed registration if the child's sex cannot be determined. We will comment on the gender recognition law and the ongoing processes where gender neutral-markers are reviewed as a possible solution for future ID number.

### 3.3.2 Implementing Our Third Recommendation in Norway: Action Point 1 – A Flexible Practice for the Birth Register

Third markers (as the German system) should not be automatic for children born with intersex variations. Garland and Travis (2018) have demonstrated that such an approach only serves to further stigmatize and 'other' these individuals and may actually cause parents to choose medical interventions in order to fit their child better into the sex binary. Germany's X-marker approach for children who cannot be placed into the sex-binary has received wide criticism.<sup>152</sup> When Sweden investigated their legal protection of intersex people, the patient organizations and other NGO's that were consulted were not in favour of introducing a third sex category.<sup>153</sup> In addition, it follows from this report that intersex babies born in Germany after 2013 registered as "other" had their legal sex changed to boy or girl very quickly. Germany's approach may be implicitly pressurizing parents to place their children into the sex binary to avoid their child being categorized as 'X'. This finding has also been supported by research by Garland and Travis (2018). Finally, research has pointed out the lack of

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<sup>151</sup> Cf. Forskrift 21. desember 2001 nr. 1483 om innsamling og behandling av helseopplysninger i Medisinsk fødselsregister (Medisinsk fødselsregisterforskrift).

<sup>152</sup> See Garland and Travis (2018); Travis (2015).

<sup>153</sup> Socialstyrelsen, *Vård och behandling av personer med intersexuella tillstånd Kartläggning av det tidiga omhändertagandet* (2017) at 78, available at <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20474/2017-1-24.pdf>, accessed 1.5.2017.

knowledge about the consequences for a child growing up in a third sex category.<sup>154</sup> We would therefore not recommend such an approach based on the needs of intersex people although we acknowledge that it might be attractive to other minority groups such as non-binary trans individuals.

Moreover, only a small minority of children with intersex variations are unable to be placed within the male/female binary. Usually, the sex of intersex babies is determined within 1-2 days by the DSD-teams.<sup>155</sup> In more difficult cases it can take months, but this is rare. The necessity of third alternatives such as an X-category for intersex-children, as in the German system, is therefore not very pressing. Rather there is a need to give parents and practitioners more time: a short period for the registration of a child places undue pressures on the parties involved. This can lead to parents making decisions about medical interventions without being given enough time to reflect on the situation. Furthermore, it may lead to ‘incorrect’ registrations of sex in the Birth Register. The form and the guidelines should therefore mention procedures for intersex cases, and ensure that the registration can be delayed if necessary and that the Birth Register can be amended. As it is a legal duty to notify the Birth Register about the sex of the child within a month, special procedures should be developed to avoid potential pressure on health personnel (and consequently parents’ decision-making processes) to assign sex where more time is required.

As the child grows older and is better able to articulate their gender identity they will be better placed to inform about their ‘correct’ sex. The Council of Europe found that the probability of wanting legal gender change for intersex people is higher than in the rest of the population.<sup>156</sup> When the Council of Europe examined existing research on the probability of developing gender identity problems for intersex people, it found that the results varied between 8.5 % and 40 % in the different studies.<sup>157</sup> Consequently, it is important that a flexible practice of birth registration is also adopted for intersex persons with regards to changing between the existing sex categories male and female.

Positively, however, Norway recently introduced the Gender Recognition Act (*Lov om endring av juridisk kjønn*) in 2015, which made it easier for intersex persons to change their

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<sup>154</sup> Socialstyrelsen, *Vård och behandling av personer med intersexuella tillstånd Kartläggning av det tidiga omhändertagandet* (2017) at 78, available at <http://www.socialstyrelsen.se/Lists/Artikelkatalog/Attachments/20474/2017-1-24.pdf>, accessed 1.5.2017.

<sup>155</sup> Mari Rian Hanger, *Finner barnets egentlige kjønn*, *Dagens Medisin*, (22/2008).

<sup>156</sup> Council of Europe Commissioner for Human Rights, *Intersex and Human Rights*, (2015) p.23.

legal gender. The process is now based on a model of self-declaration dispensing with requirements for medical or psychiatric evidence. People over 16 years old can freely apply to change their legal gender, and children between 6 and 16 years must apply together with their parents. The gender marker in the social security number will be changed to the preferred gender, if the application is approved. The Gender Recognition Act grants intersex people stronger rights to change their legal gender compared to other groups. According to the act § 6, parents or other persons with legal guardianship can apply for a change of legal gender on behalf of children under six years old who have a DSD-condition.<sup>158</sup> Their condition must be documented by health personnel. Children that can form their own views have the right to information and to express themselves before the application is made, cf. § 6.<sup>159</sup> This provision means that an intersex person can change their legal gender before the age of six, in contrast to non-intersex people.

While it is positive that an easier path to gender change exists within this act for intersex persons, it is questionable how appropriate it is to require that the DSD-diagnosis is documented by health personnel, as this is in practice medicalises a process that is, in reality, an administrative error. The concern relating to the requirement of a certificate documenting a DSD-condition is that the mere existence of a DSD-diagnosis does not necessitate a change of legal gender and thus, there is no requirement to ensure that the legal gender change is in accordance with the development of the child's gender identity. There is the danger, therefore, that in its current form Norway's Gender Recognition Act does not fully protect the best interests of the child and could leave children in a vulnerable position where they may be too young to participate in the process. However, we would recommend that Norway aligns with the Swedish provision that a legal gender change is in accordance with the child's gender identity to ensure there is no incongruence between legal gender and the child's understanding of their gender identity upon change.<sup>160</sup>

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<sup>160</sup>According to the Swedish law proposal, intersex children below 12 years old can change their legal gender, following the requirement of the submission of a certificate from a DSD-team attesting that the change is in accordance with the development of the child's gender identity and with the child's wishes, taking account of the child's age and level of maturity. The Swedish provision differs from the Norwegian model on requiring a certificate documenting the change while the Norwegian provision only requires a documented DSD-condition.

### 3.3.3 Implementing Our Third Recommendation in Norway: Action Point 2 – Removing Sex/Gender Markers From Social Security Numbers

As aforementioned, we do not recommend the introduction of third sex categories or "X"-categories automatically for intersex people. Generally, most intersex adults would not engage with a third category on identity documents such as ID Cards or passports because they do not wish to identify outside of the male/female dyad. Nevertheless, we acknowledge that other groups, for instance non-binary trans individuals, might wish this and therefore our recommendation is not designed to pass comment on the broader introduction of a third sex/gender marker.

In March 2017, the Ministry of Finance proposed to remove the gender-mark in the social security number.<sup>161</sup> The proposal is based on calculations made by the Norwegian Tax Administration (Skattedirektoratet) in 2014 that recommended that a new model must be in place by 2040.<sup>162</sup> The Norwegian Tax Administration also recommended a removal of the gender-mark in the social security number. One of the arguments is that this is the most cost-efficient model to meet possible long-term international trends to abandon systems of two legal sex categories. In the law proposal, the Ministry of Finance refers to intersex people as a group that will benefit from this system.<sup>163</sup> As third markers are not among the most prioritized issues for intersex people, we do not have strong recommendations on questions of “gendered-neutral” social security numbers. Gender marks in official documents may be discriminatory to many groups in society that challenge the stereotypical perception of sex, although we recognize that for many intersex people this is not an issue. We therefore support the law proposal on gender-neutral national identity number. We also see that Norway could be a forerunner in this domain.

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<sup>161</sup> Finansdepartementet, Høyringsnotat. Forslag til ny personidentifikator (2017), available at [https://www.regjeringen.no/contentassets/c7cc56174c6645349b847c0614119e8b/h\\_notat\\_ene\\_personidentifikator.pdf](https://www.regjeringen.no/contentassets/c7cc56174c6645349b847c0614119e8b/h_notat_ene_personidentifikator.pdf), accessed 1.5.2017.

<sup>162</sup> Skatteetaten, *Konseptvalgutredning. Ny personidentifikator i Folkeregisteret* (2015) at 8, Finansdepartementet, Høyringsnotat. Forslag til ny personidentifikator (2017) s. 7.

## 4 CONCLUSION

Evidently, there is a political consciousness within Norway that is striving to improve the lives of intersex people. However, in its current form, Norway's legal and political framework does not offer real, substantive protections for this group of individuals. Consequently, intersex people do not have sufficient protections in place against discrimination and hate crime; and most pressingly, are vulnerable to non-therapeutic medical interventions happening before they are able to give their informed consent. While the DSD-teams have very positively suggested that they are adopting a more cautious approach, this is not yet embedded within any medical and/or ethical guidelines.

In proposing options for reform, we reiterate that a model of best practice in this area contains three core elements. Consequently, we advise that *all* States should seek to implement these three recommendations in order to better protect intersex persons in a manner best suited to their jurisdiction:

1. Defer non-therapeutic medical interventions on intersex children until the individual concerned is old enough to participate in the decision.
2. Meaningful Incorporation of Intersex within Anti-Discrimination, Hate Crime and Hateful Speech Legislation by Including References to 'Sex Characteristics'.
3. Flexible gender recognition systems rather than introduction of a third sex category.

Section three of this report has considered how these three elements could be included within the Norwegian context. Consequently, our action plan contains a number of specific action points necessary to provide intersex persons with sufficient legal protections. This has included broader recommendations to legally defer interventions on children that are non-therapeutic before the child can participate in the decision, that also will apply to non-therapeutic medical intervention on intersex children, (preferring the terminology treatment that can be deferred instead of 'medically unnecessary'); broader amendments to medical and ethical guidelines with Norway; as well as more specific amendments to include 'sex characteristics' (kjønnskarakteristika) as a protected characteristic within Norway's anti-discrimination legislation, hate speech legislation and crimes that could be categorized as 'hate crime'. While these reforms are substantive, we believe they are of fundamental importance to redressing the issues faced by intersex persons.

Additionally, we would like to point out that meaningful reform within Norway requires effective communication between the State, intersex people and the medical profession. To ensure this, we advise that the above recommendations should be underpinned by five further suggestions:

1. Support and funding should be provided to establish intersex groups in Norway.
2. Legal experts, medical professionals, policy makers and the intersex community should be brought together to form a working group on the action plan that we have identified.
3. The intersex community should be consulted on any alterations to legislation or medical guidelines that purports to benefit them – this may be through the aforementioned working group.
4. There is a continued need for research with (rather than on) the intersex community that fits into the parameters of international human rights conventions.
5. There is an ongoing need for educational reform around intersex issues at a number of levels.



## References

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