

## **Submission to the High-level Working Group on Health & Human Rights of Women, Children & Adolescents**

*by Child Rights International Network (CRIN)*  
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A raft of international human rights standards address children's health-care rights. However, a failure to assert children's rights consistently in matters of consent relating to all therapeutic and non-therapeutic interventions perpetuates violations of these rights. This submission focuses on those areas of children's health-care rights that have yet to be comprehensively addressed, and the mechanisms needed to enforce them.

### **Minimum ages and consent to medical care and treatment**

#### *Right to be heard and evolving capacities*

Children are entitled to be actively involved in their own health-care from the earliest possible age. Yet a persistent presumption that children are incapable of making decisions about their own health care is emblematic of their low status as rights holders. Barriers to accessing medical services are often evident in high minimum ages. However the Convention on the Rights of the Child (CRC) recognises the value of a child's views and the need to give them weight in accordance with their age and maturity (art. 12). This approach clearly endorses the need to reject strict age requirements with regards to children's health-care rights and instead adopt a more flexible approach that takes account of individual characteristics of the child. This approach is bolstered by article 5 recognising children's evolving capacities.<sup>1</sup>

Where a child has capacity, their views should determine their treatment and care, in line with the CRC and various general comments of the Committee on the Rights of the Child.<sup>2</sup> In such circumstances a parent, or anyone else, need only be informed of the child's decision if to do so would be in the best interests of the child.<sup>3</sup> A minimum age should nevertheless be set above which everyone has this right regardless of capacity to ensure that in practice children are not denied this right into adulthood. In contexts where widespread misconceptions exist about the effects of administering or denying certain services to children, such as sexual and reproductive health and harm reduction services, a presumption of capacity should exist as the fact that a child is seeking such services to inform and protect themselves is in itself an indication of capacity. If the provider becomes concerned that the child lacks the necessary capacity while assessing their needs, a course of action which best fulfils their best interests should be taken, influenced heavily by the

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<sup>1</sup> For more details, see CRIN "Age is arbitrary: setting minimum ages", April 2016: <https://www.crin.org/en/home/what-we-do/policy/minimum-ages>

<sup>2</sup> UN Committee on the Rights of the Child, General Comment No. 4 (2003) on adolescent health and development, General Comment No. 15 (2013) on the right of the child to the enjoyment of the highest attainable standard of health (Article. 24), Draft General Comment on the implementation of the rights of the child during adolescence (April 2016).

<sup>3</sup> UN Committee on the Rights of the Child, General Comment No. 4 (2003), para. 32

child's own views.

The appropriate method of ensuring that a child's views are heard in health-related matters will vary from child to child and should be assessed on a case by case basis. However, such an assessment should consider solely whether the child has the capacity to make the particular decision at hand, rather than judge their capacity in general. A key element of this right involves access to impartial, appropriate and sensitive counselling to support the child to make informed decisions and avert parental pressure. The Committee on the Rights of the Child has emphasised adults' responsibility to find ways of learning children's views, including those who are very young, through visual, or other non-verbal communication where necessary.<sup>4</sup> In addition, the competence of those who are requesting consent should be established to ensure they can explain the issues clearly and support children and their parents in making decisions without putting pressure on them.

#### *Right to privacy and respect for confidentiality*

All children have the right to privacy and respect for confidentiality under article 14 of the CRC. This includes confidentiality in seeking medical advice, to access medical records and control who else can access those records. The right to confidential advice and counselling can extend to the right to withhold medical information from everyone except the medical professional involved, including parents. This right is particularly important where the child's safety or well-being is at stake, where the right to confidential medical counselling and advice without parental consent should be applied irrespective of age.<sup>5</sup> This has obvious applications for children experiencing violence or abuse at home, but also in seeking reproductive health education or services.

The issue of confidentiality is separate to that of decisions over the child's care. Where a child lacks the capacity to make a determination about his or her care, it may frequently become necessary for medical professionals to discuss a child's care with parents or carers, but this does not override the child's right to confidential advice and counselling.

#### **Parental consent**

In certain areas of healthcare and in a minority of complex and extreme cases, conflict may arise between a child's views and what others perceive to be in their best interests, or between children's rights and their parent's views - for instance where a child is not old enough/ mature enough to consent or refuse consent - and parents from various religious backgrounds reject life-saving medical interventions on the ground that they are forbidden by their faith.

#### *Sexual and reproductive health, harm reduction*

The right to make decisions about sexual and reproductive health is fundamental and should never be overridden by a parent or guardian regardless of age. While children may be encouraged to discuss their situation with their parents, parental consent and notification requirements are inappropriate and may discourage children from seeking help.<sup>6</sup>

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<sup>4</sup> The Committee on the Rights of the Child asserts the importance of respecting young children's evolving capacities in its General Comment No. 7 (2005) Implementing child rights in early childhood, para. 17.

<sup>5</sup> UN Committee on the Rights of the Child, General Comment No. 12 (2009), para. 101.

<sup>6</sup> The CRC's draft General Comment on Adolescence asserts that States should consider allowing children to consent to certain interventions without the permission of a parent, caregiver, or guardian,

### *Denial of treatment based on religion*

The denial of life saving treatment on the basis of religious belief has been a persistent but underreported phenomenon with regards to children's health rights. For example, in July 2011, the Canadian Medical Association indicated that 19 out of 50 States in the US retained laws that allowed faith healing exemptions to child abuse and neglect felonies.<sup>7</sup>

The CRC is very clear in its requirement for states to take "all effective and appropriate measures with a view to abolishing traditional practices prejudicial to the health of children", and in conjunction with its protections against "abuse, neglect or negligent treatment, maltreatment or exploitation ... while in the care of parents".<sup>8</sup> Furthermore, the recognition that the best interests of the child are a primary consideration in health-care decisions militates against denying children access to medical care based on their parents' religious convictions. A child with appropriate capacity may be able to refuse life saving treatment if able to weigh all appropriate information and the consequences, but for parents to act against a child's best interests in relation to health treatment is a clear violation of that child's rights.

### **Consent and access to information**

Children must receive appropriate information on all aspects of health and give their informed consent to medical treatment and care. Article 17 of the CRC includes a general obligation to ensure that the child has access to information and material from diverse sources, especially those aimed at promoting well-being and physical and mental health. Article 24(2)(e) requires that State parties take appropriate measures to ensure that children are informed about their health and various specific health issues. The Committee's General Comment on the Right to Health further establishes that this should be 'physically accessible, understandable, and appropriate to children's age and educational level'.<sup>9</sup> Yet children are routinely denied this right, in certain areas in particular.

### *Over-medicalisation*

The prescription of drugs is often an important component of health care. But over the past several years, lawsuits and investigations have cropped up around the world that raise concerns about not only testing drugs on children, but administering untested or unnecessary drugs on children. These include cases of children harmed by drug trials in which their informed consent has not been obtained, particularly in developing countries.<sup>10</sup> In addition, professional associations are expressing serious concerns about the overprescription of powerful drugs to treat children affected by ADHD or other behavioural difficulties, sometimes in combination with antidepressants, often unnecessarily, without proper information, and at an increasingly young age. Finding ever cheaper and easier ways to keep children "under control" all too often takes precedence over considering the long term effects of such treatment. Child neurologist and active opponent to the diagnosis of ADHD Fred Baughman argues that part of the problem is that since the 1980s when ADHD was first classed as a medical condition, it has since been represented as a "brain disease".

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"such as HIV testing and sexual and reproductive health services, including education and guidance on sexual health, contraception and safe abortion".

<sup>7</sup> Canadian Medical Association, "Too much leniency to 'faith healing' parents", 11 July 2011:

<http://crin.org/resources/infodetail.asp?id=25433>.

<sup>8</sup> UN Committee on the Rights of the Child, Art. 19(1)

<sup>9</sup> Para 58. Available at: [https://www.crin.org/en/docs/CRC-C-GC-15\\_en-1.pdf](https://www.crin.org/en/docs/CRC-C-GC-15_en-1.pdf)

<sup>10</sup> CRIN case summary, Rabi Abdullah v. Pfizer, 2009. Available:

<https://www.crin.org/en/library/legal-database/rabi-abdullahi-v-pfizer-inc>

This perception has made it “logical for the public to think that a pill is going to be the solution,” which he adds, “is to deceive the public [as] it pre-empts [their] right to informed consent in every single case.”<sup>11</sup>

#### *Access to information and LGBT rights*

Children should receive education on sexual and reproductive health. Sexual and reproductive health education in school is one of the most important ways to help children understand risks, improve their reproductive health and make informed decisions regarding their sexual and reproductive health lives. This applies equally to LGBT children, and limiting access to information on these issues can have a profoundly negative effect on children’s physical and mental health. Yet legislation and policy-making aimed at limiting children’s access to information about LGBT issues, in the name of protection, is increasing in prevalence.<sup>12</sup> Such laws clearly have a discriminatory and harmful effect on the rights of LGBT children to equal protection under the CRC, but they also have a harmful effect with regards to access to health information.

#### **Issues of consent affecting everyone, with particular implications for children’s rights**

Some issues of consent affect both children and adults, either because they have been assessed as lacking capacity or because an issue has yet to be defined in human rights standards.

#### *Toxic trespass*

All human beings endure the trespass of toxic chemicals. We breathe air, eat food and drink water which contain chemicals without giving our consent to their presence in our bodies. Children are particularly vulnerable because of their developing bodies.<sup>13</sup> Baskut Tuncak, UN Special Rapporteur on Toxics has highlighted that this has created a “silent pandemic” of disease and disability affecting millions of children worldwide.<sup>14</sup> Children are exposed to toxic chemicals in many circumstances, even before they leave their mother’s womb. They are also exposed through the use of hazardous pesticides in food production or when engaging in agricultural work, or when playing nearby the fields that has just been sprayed, but also at home because of the cooking facilities, the pesticides/herbicides used, and through the substances used in toy production...<sup>15</sup>

The Convention of the Rights of the Child (CRC) explicitly requires States to provide “adequate nutritious foods and clean drinking water, taking into consideration the dangers and risks of environmental pollution” (art. 24). In its General comment No. 15, it urges States to take measures to address the dangers and risks that local environmental pollution poses to children’s health in all settings.<sup>16</sup> General comment No. 16, on state obligations regarding

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<sup>11</sup> CRIN, “Children’s rights and the other kind of drug use”, 16 May 2012. Available at: <http://www.crin.org/resources/infoDetail.asp?ID=28448>.

<sup>12</sup> CRIN, “Laws restricting children’s access to information”, March 2014. Available at: <https://www.crin.org/en/library/publications/censorship-laws-restricting-childrens-access-information>

<sup>13</sup> The World Health Organisation estimates that more than 1,700,000 children under the age of five died prematurely from modifiable environmental factors.

<sup>14</sup> See the UN Special Rapporteur on Toxics’ children’s rights-focused report: <https://www.crin.org/en/library/publications/environment-childrens-rights-focused-report-un-special-rapporteur-toxics>

<sup>15</sup> See cases of Pesticides contamination at: <https://www.crin.org/en/home/what-we-do/crinmail/week-childrens-rights-crinmail-1487>

<sup>16</sup> UN Committee on the Rights of the Child, General Comment No. 15 (2013), para. 49

the impact of the business sector on children's rights, is also relevant, stating that "Childhood is a unique period of physical, mental, emotional and spiritual development and violations of children's rights, such as exposure to (...) unsafe products or environmental hazards may have lifelong, irreversible and even transgenerational consequences".<sup>17</sup> It adds that "environmental degradation and contamination arising from business activities can compromise children's rights to health, food security and access to safe drinking water and sanitation".

### *Compulsory mental health treatment and detention*

The Convention on the Rights of Persons with Disabilities prohibits the use of disability - including mental disability - as a ground of deprivation of liberty. The detention of a person on the basis of mental health or disability may also constitute discrimination under article 2 of the UN Convention on the Rights of the Child and article 26 of the International Covenant on Civil and Political Rights. Where detention is authorised for children in circumstances in which it would not be permitted for adults, this raises further issues of discrimination on the basis of age.

When children are detained on mental health grounds in the civil justice setting, it all too often constitutes arbitrary detention. In addition, the requirement for a periodic review often does not apply to children detained on mental health grounds and sometimes does not apply to children where it would apply to adults. Where involuntary detention is justified as "treatment" or for a person's "own safety", such cases constitute a paternalistic act carried out regardless of consent and without consideration of a child's capacity. If a child has the capacity to make decisions about their care, then respect for their views should determine how they ought to be treated, and informed consent should be obtained. Where a child lacks capacity to consent, any decision concerning the child must be made in their best interests, influenced by their views and with respect for their rights. Patients should be supported to obtain access to effective remedies, including initial and periodic judicial review of their detention.

Where a person with a mental illness is charged with or convicted of a criminal offence it would have to be justified in the same manner as any other criminal detention, that is, as set out in the UN Study on Violence against Children, this should "ensure that detention is only used for child offenders who are assessed as posing a real danger to others, and then only as a last resort, for the shortest necessary time, and following judicial hearing, with greater resources invested in alternative family-and community-based rehabilitation and reintegration programmes".<sup>18</sup>

### *Euthanasia*

The working group should consider the issues of euthanasia and assisted dying. In many countries restrictions affect adults as well as children, but children may experience additional minimum age barriers. Yet a child living with a terminal illness, and the attendant knowledge of their circumstances and condition, is likely to understand better than any adult the consequences of their decisions in this area of their lives. Where a terminally ill child wishes to undergo euthanasia and a medical professional judges them to be capable of making this decision, provided appropriate safeguards are in place and always as a last resort, age should not be a factor in granting or denying this wish. The child's right to participate in decisions about their medical care from the youngest possible age and the requirement to

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<sup>17</sup> UN Committee on the Rights of the Child, General Comment No. 16 (2013), para. 4(a)

<sup>18</sup> Paulo Sérgio Pinheiro, Independent Expert for the United Nations Secretary-General's Study on Violence against Children, World Report on Violence Against Children, p. 218.

respect children's evolving capacities should be the predominant considerations. A number of countries have now recognised that blanket bans and restrictions on euthanasia are a breach of human dignity when they cause suffering by forcing a person to continue living despite untreatable pain and an express wish to die.<sup>19</sup>

For more information, read CRIN: Belgium - age restrictions lifted on euthanasia:  
<https://www.crin.org/en/library/publications/belgium-age-restrictions-lifted-euthanasia>

### **Consent to non-therapeutic interventions**

Practices which violate children's physical integrity, when carried out for no therapeutic reason and without the child's free and informed consent - regardless of age - are a violation of the child's physical integrity and dignity and should constitute a criminal assault. These range from female genital mutilation, non-medical male circumcision, hormone treatments, "corrective" surgery performed on intersex children, conversion therapies carried out on LGBT children, and sterilisation of children with learning disabilities. Forcing a child to undergo a procedure which serves no therapeutic benefit is a violation of their right to protection from all forms of physical or mental violence, injury or abuse (CRC art. 19), the highest attainable standard of health (CRC art. 24), and ultimately their survival and development (CRC art. 6)

Furthermore, the Committee on the Rights of the Child has condemned the use of religion as a justification for overruling the child's right to refuse consent to practices that affect their physical integrity, through a negative interpretation of children's best interests, both in its General Comment No.14 on best interests<sup>20</sup> and General Comment No.8 on the right of the child to protection from corporal punishment.<sup>21</sup>

There is increasing recognition of some of these violations by UN treaty bodies,<sup>22</sup> but male circumcision continues to be overlooked.

#### *Male circumcision*

CRC article 24 designates the use of health care for therapeutic and preventative reasons. As non-consensual, non-therapeutic male circumcision is being challenged from a children's rights perspective, claims have emerged that sufficient preventative health advantages from circumcision at an early age to justify parental consent, but the evidence for this is disputed among health professionals. Paediatricians and professional associations from 17 countries have agreed that existing medical research does not justify this "surgery before boys are old

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<sup>19</sup> For example Belgium, [Canada](#) and [Germany](#)

<sup>20</sup> CRC General Comment No. 14 (2013) on the right of the child to have his or her best interests taken as a primary consideration (art. 3, para. 1), CRC/C/GC/14, para. 4.

<sup>21</sup> CRC General Comment No. 8 (2006), The right of the child to protection from corporal punishment and other cruel or degrading forms of punishment (arts. 19; 28, para. 2; and 37, inter alia), CRC/C/GC/14, para. 29.

<sup>22</sup> The Committee on the Rights of the Child asserted for the first time that non-consensual intersex surgeries violate physical integrity and constitute a harmful practice during its review of Switzerland in February 2015, CRC/C/CHE/CO/2-4, paras. 42 & 43.

enough to decide for themselves.”<sup>23</sup> The majority of peak medical bodies also agree that the side effects and complications of male circumcision outweigh potential benefits.<sup>24</sup>

The first clear legal challenge to non-therapeutic male circumcision was made by a district court in Cologne, Germany in June 2012, which held that children's rights should be upheld above the religious freedoms of parents.<sup>25</sup> The court's argument has a parallel in the CRC article 14 which requires States to respect children's rights to determine and follow their own convictions under parental guidance - as opposed to control or determination - in accordance with the child's evolving capacities. Accordingly, parents' rights should not extend to the determination of a child's religion or irreversible decisions on the basis of religion or conscience.

## **Access to justice**

Without access to justice - broadly defined to include remedies as well as practicalities such as legal aid - rights are illusory. The Committee on the Rights of the Child has asserted that economic and social rights as well as civil and political rights should be equally justiciable.<sup>26</sup> Children should be empowered to access all appropriate courts, legal, judicial or other complaints mechanisms to enforce their right to health. They should be able to access remedies where their rights have been breached, including preventative remedies where they can challenge denials of access to health services.

To ensure that children are able to engage with these systems, well developed and free legal aid and assistance should be in place to provide support as well as a free 24-hour helpline to give children a chance to talk to someone and discuss their options. Children should know of the existence of these complaints mechanisms and how to use them. Health facilities should provide children with information about their rights and all means of challenging any violation of their rights. Steps should immediately be taken to protect child victims from further harm and to link them with services they may need to reach a full physical and psychological recovery.

## **Recommendations**

CRIN urges the working group to:

- Recognise that capacity, not age, should determine whether a child can consent or reject treatment and care and this should consider solely their capacity to make the decision at hand.

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<sup>23</sup> Frisch, M. *et al.* (2013), “Cultural Bias in the AAP's 2012 Technical Report and Policy Statement on Male Circumcision”, *Pediatrics*, Vol. 131, No. 4, pp.796-800. Available at:

<http://pediatrics.aappublications.org/content/131/4/796.full.pdf>

<sup>24</sup> Nyaundi, P.M. (2005), “Circumcision and the rights of the Kenyan boy-child,” *African Human Rights Law Journal*, Vol. 5, No. 1, pp.171-181. Available at:

<http://www.chr.up.ac.za/index.php/ahrlj-contents/volume-5-no-1-2005.html>

<sup>25</sup> Cologne Regional Court, Wa. 151 Ns 169/11

<sup>26</sup> CRC General Comment No. 5, para. 25

- Urge States to recognise a legal presumption of capacity for all children, not just adolescents, seeking out sexual and reproductive health services and harm reduction services, and eliminate parental notification requirements.
- Prohibit and enforce prohibitions on harmful practices which serve no therapeutic purpose and have an irreversible impact.
- Prohibit all non-therapeutic procedures carried out without the child's free and informed consent, including made circumcision, 'corrective surgery' for intersex children and forced sterilisation.
- Urge States to follow Special Rapporteur Tuncak's recommendations about their obligations to prevent children from being exposed to toxics and pollution. As part of their human rights due diligence, businesses should also identify, prevent and mitigate exposure of children to toxics through their activities, products or business relationships.
- Recognise that the only justification for locking up a child in relation on mental health grounds in the criminal setting is that they have been assessed as posing a serious risk to others' or their own safety and that risk cannot be reduced to an acceptable level without their detention. In the civil setting children should only be detained with their consent or, where they are not able to consent, in the best interests of the child, with respect for all their rights.
- Develop standards elaborating children's rights in relation to euthanasia and assisted dying.
- Ensure children are empowered to access all appropriate courts, legal, judicial or other complaints mechanisms to enforce their right to health and receive appropriate information and support to do so. This must include access to remedies.